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Oldfield, S. J. (2010). *Adjustment of parents of children with asthma or Type 1 diabetes*. PhD thesis. Oxford Brookes University.

OXFORD BROOKES UNIVERSITY

**Adjustment of Parents
of Children with Asthma or Type 1 Diabetes**

A thesis submitted in part
fulfilment of the requirements for
the award of a PhD

by

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December, 2010

ACKNOWLEDGEMENTS

Grateful thanks are due to my supervisors, Professor Guida de Abreu and Dr. Luci Wiggs, as without their continuing support, the completion of this study would not have been possible. Their thoughtful comments and facilitative approach have helped me to learn so much, and to strive to achieve my best.

I would also like to acknowledge the support from my original supervisors, Professor Terezinha Nunes and Dr. Ursula Pretzlik, who helped to nurse this study into being and who were most helpful in the early stages of data collection and analysis.

I am also most grateful for the contributions of all the parents and other participants of this study, who shared so many thoughts, feelings and experiences with me, enabling this study to include such rich data.

Finally, I would like to thank family and friends for their ongoing support and understanding, as well as that of the health care staff who supported the study, and staff at the School of Health and Social Care. Their help in so many ways, made this study not just a possible, but an enjoyable journey.

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ABSTRACT

Adjustment of parents of children with a chronic illness is an under-researched area, particularly using qualitative methodology. This is the case in relation to all chronic childhood illnesses, including asthma and Type 1 diabetes. These two illnesses are both increasing in prevalence and are highly relevant exemplars of illnesses that have a significant daily impact on the lives of children, parents and families. A mixed categorical / non-categorical approach was taken in this study, which has the advantage of highlighting both illness-specific and general features of parents' experience of the child's illness. Understanding these similarities and differences will help clinicians to focus parent and family support appropriately and also will help stimulate and inform future research efforts. Two further issues that influenced the aims of this study are the lack of theoretical coherence and poor clarity with regard to the meaning of parental adjustment and factors that influence it.

The aim of this qualitative study was to investigate the adjustment of parents of children with asthma or Type 1 diabetes, and through this, to develop new theory about parents' adjustment. This theory was intended to help explain the parents' experience of adjustment and identify factors relevant to their adjustment outcomes.

A grounded theory approach was used, set within a constructivist paradigm. The purposive sample included 32 mothers, 7 fathers and one grandmother of a child with asthma or Type 1 diabetes. Findings from observations of three multi-disciplinary team meetings following clinics and interviews with three specialist nurses and a support group leader contributed to refinements made to the parent semi-structured interview schedule.

In-depth semi-structured interviews were used to investigate respondents' perspectives in relation to their experience of the child's illness and illness episodes, and the effects on their own and family life. Data were analysed using thematic analysis, guided by principles of grounded theory such as constant comparison. NVivo qualitative data analysis software was used to assist in the data analysis process.

A new theory was developed, which incorporates a dynamic model, reflecting how parents experience adjustment in the face of new events over the course of time, in many facets of their personal life, as a parent, and in family life. The four steps of goals, events, processes and outcomes reflect findings that arose during the empirical analysis, which was organised around four major dimensions of the parents' experiences.

The theoretical model developed in this study is a useful framework for future research and clinical practice, offering a coherent framework for a field of research that is very disparate in objectives and theoretical orientation. Clinicians may use the model as a basis of exploring parents' adjustment, not only in relation to illness-specific issues, but also in relation to supporting the development and use of coping resources and assessing whether the parents' goals are being met in other aspects of their lives. It is a model that can be used by the multi-professional health and social care team, which could be beneficial for integrated care of the child and family.

CHAPTER 1: INTRODUCTION

1.1 BACKGROUND AND PURPOSE OF THE STUDY

The purpose of this qualitative study is to investigate the adjustment of parents of children with asthma or Type 1 diabetes, both of which are chronic illnesses with a significant disease burden, and with rising prevalence in Europe (Anderson, 2004; Patterson et al., 2009; Green et al., 2000) and in many countries worldwide (Asher et al., 2006; Soltesz et al., 2007). The term ‘chronic illness’ does not have a widely agreed definition, although in a comprehensive analysis of researchers’ understanding of this term, Perrin et al. (1993) recommend that the definition should refer to an illness lasting longer than 3 months or that is expected to last longer than this time. They further recommend that reference is made to the extent to which functional impairment and medical attention differs from that of a child of the same age.

Although there is a fairly extensive body of research investigating the impact of a chronic illness on children (Lavigne and Faier-Routman, 1992,1993; Drotar, 1997; Wallander & Varni, 1998), little attention has been paid to the experience of parents of these children (Barlow and Ellard, 2006). Studies that have been undertaken have mostly been descriptive, for example surveys or correlational designs, and have highlighted that these parents are more likely to experience mental health problems than those in the general population. For example, a major Canadian epidemiological survey of mothers and fathers of over 1800 families of children with a chronic illness undertaken in 1987 by Cadman et al. revealed that mothers of chronically ill children experienced more negative affect than those without a chronically ill child. Their results also showed that both mothers and fathers were 2-3 times more likely to seek mental health treatment than parents of well children.

A review by Wallander and Varni (1998) however explains that significant variability has been found in the adjustment of parents, and calls for further research that will help to identify processes that reveal why parents might or might not experience adjustment problems. It seems likely that factors such as parents’ individual differences, child age, illness type and features or other factors could influence outcomes for such parents. However, almost no qualitative research has been undertaken on this topic that could help to provide insights into these questions; most research has used existing measures of psychological functioning, which is not able to reveal what has led to adjustment strengths or difficulties.

1.2 EXAMINING THE CONCEPT OF ADJUSTMENT

In the context of chronic illness, adjustment seems to be understood as the psychological and behavioural response of an individual or family to the internal and external stressors associated with the illness experience, which will be influenced by their coping skills and resources. Adaptation is similarly and widely understood (for parents) to be “the degree to which parents cope psychologically, socially and physiologically with the chronic illness of their child or children” (Hentinen and Kyngäs, 1998, p.317). Quality of life (QoL) seems to be an aspect of adjustment, and is frequently referred to when assessing the impact of a chronic illness on individuals or family members. However this has no clear agreed definition (Gill and Feinstein, 1994). In their review of medical literature, Gill and Feinstein noted that only 15% of authors explained their understanding of this concept. According to Eiser and Morse (2001), this is further complicated by the fact that medical and psychological literature use different meanings for the same term; they explain that QoL psychological literature typically focuses on assessing the individual’s subjective view of their experiences, lifestyle and future hopes, whereas medical literature is inclined to focus on the individual’s physical, emotional and general wellbeing. Therefore, although there is some commonality of these various terms, there is a general lack of clarity of meanings.

A further limitation of literature in this area is that there is a strong focus on maladjustment, rather than positive adjustment of parents (normally the mother) (Barlow and Ellard, 2006). This is despite a plea by Eiser (1990) that research needs to move away from chronic illness models focusing on psychopathology. It would be beneficial to identify features of good adjustment and what facilitates this, rather than only on the extent or prevalence of maladjustment. Furthermore, there is no consistency in the literature about which measures are used to identify maladjustment; therefore, this body of evidence lacks conceptual coherence about what is being assessed.

As illustration of this point, in an initial review of the literature to identify the background literature for this study, 29 different measures were counted in 25 studies measuring parents’ adjustment. Usually these were investigations focusing on child adjustment, where parental adjustment was viewed as a correlate. General measures of anxiety and depression were commonly used, the two most frequent (and only used by 3 authors in each case) being the Psychiatric Symptom Index (PSI) (Okun et al., 1996) and the Global Symptom Index (GSI) (Derogatis and Melisaratos, 1983).

Furthermore, although most authors seemed to be making reference to a similar or the same variable, different terms were used to define what was being assessed, such as adjustment, adaptation, coping and quality of life. It is therefore difficult to compare study findings and draw conclusions from these. No research was identified that defined specific features of good or less good adjustment of parents. Therefore, this reinforces the value of examining in this study the features of adjustment from parents' perspective.

1.3 THE CHOICE OF THE ILLNESS GROUPS OF ASTHMA AND TYPE 1 DIABETES

There is a longstanding debate in the body of research on the psychological impact of chronic illness about whether there is sufficient similarity between the experiences of individuals with different illnesses and their families to combine them within a sample; it has been (and still is) more typical for individual child conditions to be studied within a single sample (Lavigne and Faier-Routman, 1993). These two approaches are termed non-categorical and categorical approaches respectively (Stein and Jessop, 1989).

In the non-categorical approach, generic factors common to the experience of different types of chronic illness are investigated. An example of one non-categorical study is by Silver et al. (1998); they proposed that functional limitations, reliance on compensatory mechanisms and service use or need above routine care should be used to classify children into groups, rather than according to specific illnesses. Typically, non-categorical studies include samples of children and/or parents where two or more childhood chronic illness groups are represented, with the aim of increasing the ability to discover commonly shared experiences across several illness types (e.g. frequent hospital visits, changes to family lifestyle) and how these relate to adjustment or maladjustment in the children (or their parents or family). Stein and Jessop (1989) argue that there are two advantages of this approach. Firstly, a focus on the common psychosocial variables across illnesses may yield powerful and widely generalisable assessment and intervention measures and programmes. Secondly, greater statistical power can be obtained through the combination of discrete, differing clinical samples.

Nevertheless, some researchers consider that not all illness experiences are common, and an advantage of the categorical approach according to Mullins et al. (1995) is that it allows for greater precision in modelling interrelationships between variables. The significance of disease-specific characteristics relating to illness course, task demands, phase of disease,

functional limitations and developmental stage for adjustment may be determined to a greater level. For example, Walker et al. (1992) found that specific disease features (whether the outcome would be fatal or if a cognitive impairment was associated with the illness) were associated with different stressors and responses, thus differences in adjustment.

Some researchers adopt a combination of the above approaches, where participants are recruited from a range of child chronic illness groups, initially investigating adjustment in the sample as a whole (perhaps focusing only on functional differences), then separately by disease group. In their meta-analytic review, Lavigne and Faier-Routman (1992) urged researchers to design studies that combined categorical and non-categorical approaches. They argued that combining the two approaches could not only identify specific factors but also control for more general factors that could influence adjustment. This also has the advantage of highlighting disease-specific differences that may have useful clinical applications to this population, although clearly larger sample sizes would be needed in such studies than in those adopting only a categorical approach.

Therefore, it is argued that there is value in examining similarities and differences in two groups of participants with different chronic illnesses in the current study. Qualitative studies such as this provide opportunities for in-depth analysis of data, and consequently significant potential to offer new insights into illness-specific and illness-general factors that influence children's and parents' experiences.

These two specific illnesses were selected for a number of reasons. Firstly, both have a high prevalence in the UK and worldwide. According to Asthma UK (2009), 1.1 million British children are affected by asthma, or one in ten children; it is the most prevalent chronic childhood illness in the UK. Type 1 diabetes is relatively common, with the prevalence increasing; in the UK, this has doubled every 20 years since 1945 (Diabetes UK, 2004) and again doubled in the last decade (Soltesz et al., 2007). The recent sharp increase in incidence has been reported to be highest in children under the age of five (Milton et al., 2006). The incidence of asthma is also reported to be increasing in young children, although overall it peaked in the general population of the UK in the 1990s (Anderston, 2005). Thus, the burden of these illnesses is significant, and findings of this study will be applicable to a wide population.

A second reason for selecting these illnesses is that both have a significant impact on the child's life, and therefore on the lives of their parents and families. Children with asthma may experience frequent episodes of ill health, which can impact on their lives and educational

attainment. Although it has been found that greater frequency of school absence is widely reported for children with asthma, especially when more severe (e.g. Doull et al., 1996; Moonie et al., 2006), school absence does not fully account for children's educational difficulties. For example, Liberty et al. (2010) reported in their prospective study in New Zealand, that entering primary school with asthma predicted a significantly lower reading ability (by an average of 6 months) after one year, in comparison with healthy peers. This result remained after taking into account co-variables such as asthma severity, absenteeism and socioeconomic status. Therefore, there are likely to be other factors impacting on these children's lives besides school absence that affect attainment. Similar findings of lower educational attainment have been reported by McCarthy et al. (2003) in relation to children with diabetes. Educational attainment scores were significantly lower than peers in children with diabetes, particularly those with poor metabolic control, hospitalisations for hyperglycaemia, parent ratings of behaviour problems and lower socio-economic status.

The treatment demands on children with asthma or diabetes significantly impact on their daily lives as well. Children with asthma need to undertake regular preventive activities and interventions to relieve symptoms. These include the need to measure peak expiratory flow (to assess current lung function), administer medications ('preventer' inhalers - normally a steroid - taken regularly and 'reliever' inhalers - normally a bronchodilator - taken as needed), avoid allergens (e.g. pet dander), make dietary changes (if hyper-responsive to specific food allergens), and/or moderate and take 'preventer' inhaler before exercise (if asthma attacks are induced by exercise) (Currie et al., 2005). Some children may additionally receive medication via nebulisers (although these are usually given in hospital in emergencies) (British Thoracic Society, 2008). Asthma can therefore significantly impact on daily life in terms of exercise, activities and diet, added to the self-care activities listed above within a daily routine. Additionally, children with severe or 'difficult' asthma may have poor lung function which leads to restrictions in some activities. They may be prone to regular asthma attacks, which are often unpredicted and with no obvious cause; these may be life-threatening and require hospital admission. Thus, a range of factors may lead to pathopsychological sequelae for children and the families who need to support them.

Children with Type 1 diabetes similarly need to undertake a range of self-care interventions each day. These include testing blood glucose levels at least once daily, having subcutaneous insulin injections two or three times daily (sometimes more) and rotating the locations of injection sites, following a careful diet high in complex carbohydrates and low in fat, minimising intake of simple carbohydrates (such as sweets), eating regular meals (although

less necessary on some insulin administration systems), and adjusting exercise against insulin administration and food in accordance with blood glucose readings.

Blood glucose is often difficult to control, because of physical changes with growth and maturity (meaning insulin requirements change, especially around puberty) and changes of routine. Most children experience mild or moderate 'hypos' on a regular basis (due to too much administered insulin or exercise relative to calorie intake), although generally children and parents recognise the onset of symptoms, and the child recovers quickly after consuming something sweet. More extreme variations of blood glucose levels may result in severe symptoms requiring hospital admission. Children need to attend regular clinic appointments, and have regular blood tests for HbA1c levels (a measure of long-term blood glucose regulation).

Good blood glucose regulation is important in order to prevent or reduce risks of long term complications that typically shorten an individual's life by about 20 years (Patterson et al., 2009); the better the blood glucose control, the later any complications are likely to become evident. Currently there is no cure, although there has been some encouraging experimental work involving pancreatic islet cell transplantation (Roberts, 2004). The management of this illness therefore requires a high degree of attention and intervention by the child and parents, as well as unpleasant and painful treatment interventions with much effort and concern being focused on blood glucose regulation.

These descriptions illustrate that although asthma and Type 1 diabetes (hereafter referred to as diabetes) are similar in many ways (for example the need for regular treatment, the potential for changes in health state, lifestyle and activity implications), but also vary in other ways that might affect children's and parents' activities of life and psychological functioning. These include the whether or not the treatment is painful and unpleasant; in asthma it is not, but it is in diabetes. Hope of recovery also differs; asthma has a variable course, and some children's asthma gets better with age or disappears, whereas children with diabetes cannot expect this at the moment. The long term impact of asthma may be minimal or not too serious (e.g. some reduction of lung function if asthma was poorly controlled in childhood), whereas children with diabetes may have vascular damage that can be detected as early as 12 years of age through routine retinal scanning (NICE, 2004). The potential for children to undertake active sports or go to certain environments (such as zoos) is unlikely to be affected in diabetic children, although this might be the case with asthmatic children. Also, the age of onset in asthma is typically earlier in life than in diabetes, helping to highlight developmental differences in child and family response at diagnosis. Finally, unexpected, life-threatening

illness episodes are somewhat more likely in asthmatic children with greater illness severity than in diabetic children. All of these factors may have significance for child and parent adjustment.

These similarities and differences enable a range of illness features to be considered, some of which may be applied to other common childhood chronic illnesses. For example, juvenile rheumatoid arthritis has some similarities in terms of impact to asthma, in that its course is variable, with differing degrees of severity and is likely to affect physical functioning. Cystic fibrosis has some features of diabetes, in that regular medication is needed and intrusive treatment is required to prolong a shortened lifespan. Therefore, asthma and diabetes may be seen to some extent as exemplars that have features applicable to other chronic illnesses.

1.4 SUMMARY OF THE OVERALL RATIONALE FOR THE STUDY

Chronic illnesses such as asthma and diabetes impose enduring and important life stressors that can profoundly disrupt the lives of children. This is a significant concern, not only for the emotional well-being and adjustment of each family member, but also for disease management. Parents of children with asthma or diabetes are responsible for the physical and emotional care of these children on a daily basis. Their continuous support is needed to help their child cope with the very significant demands of the illness. In addition, children, their parents and other family members such as siblings influence one another in transactions; thus an understanding of the adjustment of all family members is needed.

In consideration of this point, it is surprising that so little attention has been paid to parent and family adjustment, with the exception of maternal adjustment. Furthermore, there has not been a review in the last decade that has considered the influence of child chronic illness and adjustment on parent and family adjustment or functioning, although several have considered the reverse. The reviews in the previous decade that have focused on the adjustment of children with a chronic illness make reference to the influence of parent adjustment or family functioning on child adjustment (Lavigne and Faier-Routman, 1992,1993; Drotar, 1997; and Wallander & Varni, 1998). However, Wallander and Varni are the only authors to have reviewed any of this literature.

Investigations of interpersonal and family processes at a transactional level, in situations where the child has a chronic illness, are also relatively rare. Kazak (1989) recommended the use of family systems models in future research and practice, in order to better understand

how families of children with chronic illnesses cope with and adapt to the child's illness. Unfortunately, there has been little research relating to this recommendation, although family functioning is argued to be an important variable in investigating child and parent adjustment.

These considerations emphasise the importance in this study of not just considering the parent's experience concerning themselves, but also that of other family members and of relationships within the family. Families, like individuals, change and develop over time. Eiser (1990) argues that researchers need to move away from focusing on mother-child interactions alone, and instead investigate reciprocal relationships between all family members. It is important therefore in the present study to consider this point.

Finally, it has been noted that much of the research in this area focuses on measurements of adjustment at a single point in time. This study will offer opportunities to investigate parents' perceptions of the child's and family members' experiences over the course of the illness, although from a retrospective viewpoint. This is likely to offer important insights into the dynamic nature of parent adjustment to the child's illness. This study will be therefore important not just for the development of new theory, but for the potential clinical applications in the future.

1.5 OVERVIEW OF THE THESIS

This introduction will be followed by a review of the available literature, providing a more in-depth examination of the body of evidence than has so far been presented. This will be followed by a methods chapter that provides a detailed outline of the study objectives and methodology. Each of the four results chapters will analyse data relating to different sets of themes that have emerged from the thematic analysis, followed by a presentation of components of the theoretical model that will be proposed and discussed in the final chapter.

CHAPTER 2: LITERATURE REVIEW

2.1 BACKGROUND TO AND SCOPE OF THE REVIEW

In Chapter 1, an introduction to the literature on this topic was offered. These areas of evidence will now be explored further. This Chapter will present, examine and discuss the available literature in greater depth, where of particular relevance to this study. The review will focus on a range of literature relating to adjustment of parents of children with a chronic illness, although there is a particular focus on research where the child has asthma or Type 1 diabetes. Most of the research is quantitative, with a smaller body of qualitative literature. Whilst there are some studies that exclusively investigate parents' adjustment to having a child with a chronic illness, there is further literature on the conceptually related concepts of parents' quality of life and family functioning. The relevance of this peripheral literature and its relationship to parent adjustment will be discussed.

Initially, quantitative literature relevant to mothers' and/or fathers' adjustment was selected where the inclusion and exclusion criteria were met (as described in the next section). When considering this body of evidence, it was found that whilst some focused on parent adjustment alone, others related to the adjustment of child and parent together. In the latter group of studies, most authors first calculated correlations between measures of child and parent adjustment, then investigated parent adjustment variables as among a range of predictors or correlates of child adjustment, using statistical tests such as logistic or hierarchical regression. Therefore, in the context of this study, these studies offered less useful findings on parent adjustment, although some illustrative examples of these studies will be reviewed.

Qualitative research will then be reviewed. This body of literature centres on parents' experiences, concerns, challenges, coping strategies and quality of life; these are all topics likely to be relevant to understanding parents' adjustment to having a child with a chronic illness. Although there is relatively little qualitative research, studies have been published in both health profession and psychology journals in a range of countries, offering insights on parent perspectives across different cultures and different professional perspectives.

Research at a systems level will also be reviewed, where studies investigated experiences of parent-child dyads, couples and family systems. The latter tended to relate to how dyadic or family functioning were affected when a child had a chronic illness.

Following the review of literature, consideration will be given to implications for chronic illness research in general, and in relation to asthma and Type 1 diabetes. It will be important to consider whether there are significant differences between parents' adjustment in different illness groups, and thus whether it has been found to be useful to separately investigate adjustment (or related concepts) in parents from different child illness groups. Furthermore, it will be useful to consider how different researchers understand these concepts, as this will offer opportunities for comparison with the findings and conclusions of the present study.

2.2 LITERATURE SEARCHING STRATEGY

Literature searches were carried out using the databases of Cinahl, Pubmed and PsycInfo, including the initial key words of chronic illness, chronic disease, Type 1 diabetes or asthma, parent, mother or father. No limits were selected, other than the language being in English. The above search terms were combined with the key words of adjustment, adaptation, family functioning and quality of life. Reference lists were scanned for any further significant studies. It was noted that the number of qualitative studies identified was small, which could have been explained by the search terms possibly reflecting previously identified constructs (as is common in research taking a deductive approach); as qualitative research is more likely to adopt a more inductive approach, the search terms experience and qualitative were added to the initial key search terms. This resulted in identification of a number of further studies.

As explained in Chapter 1, no literature reviews were found on the adjustment of parents of children with a chronic illness. However, some were found on child adjustment, although not undertaken recently (Lavigne and Faier-Routman, 1993; Drotar, 1997; Wallander & Varni, 1998). Only one of these (Wallander and Varni, 1998) also reviewed literature on parent and family adjustment. Sub-sections on parental adjustment and its correlates, adjustment within family systems, and risk factors for parental adjustment were included in this review, although discussed in the context of evidence relating to the authors' conceptual model on children's adjustment to chronic physical disorders. Therefore, the overall focus of the review was on child rather than parent or family adjustment. A review by Barlow and Ellard was published in 2006 on the psychosocial wellbeing of children, their parents and siblings, but this only reviewed existing reviews that had already been identified above or were not relevant to the present study (including on child and/or family members' experiences of illnesses such as childhood cancer or learning difficulties). No new research of relevance to the current study had been reviewed.

A further literature searching strategy was to use the Web of Science author citation search, based on the relevant literature reviews identified above. Although hundreds of citations were found, this strategy confirmed the original finding that no relevant reviews had been undertaken more recently that considered parent adjustment, although some further relevant research studies were identified.

The literature about parents was then categorised according to whether the research focus related to adaptation, adjustment, quality of life, family or dyadic functioning, or in the case of qualitative research, any focus on the experiences of parents. The literature was further divided into quantitative categorical, non-categorical, mixed design and qualitative research. Inclusion and exclusion criteria were then applied. As mentioned earlier, research studies were included where the authors had taken a non-categorical approach and where experiences of parents of children with asthma or diabetes were included. In addition, where the chronic illness in a study had some features in common with those of asthma or diabetes, these were included as it was more likely that parents' experiences would be similar to those of parents of children with asthma or diabetes. Although research has shown that there are more similarities than differences in the experiences of parents of children with chronic illnesses (Stein and Jessop, 1989), other research shows that features of an illness can influence adjustment significantly (Mullins et al., 1995).

Specifically included were studies where the child had juvenile rheumatoid arthritis (JRA) or cystic fibrosis (CF). Although JRA is now more often referred to as Juvenile Idiopathic Arthritis (JIA) (Duffy et al., 2005), research on parent adjustment has to date only used the terms JRA or more rarely, JCA (juvenile chronic arthritis). The former is the original American term and the latter the former European term. In both JRA and CF, in common with diabetes and severe asthma, the child requires regular clinic attendance, daily treatment management interventions (some of which are intrusive) and has no cognitive impairment. It could be argued that cystic fibrosis differs too much from asthma and diabetes to include in this review because, in common with cancer, it is a life-limiting condition and might affect parents' adjustment differently. However, life expectancy for children with this condition is continuing to increase beyond early adulthood to mid-adulthood, with the median survival age currently being 35 years (Cystic Fibrosis Trust, 2010), and survival rates have been increasing significantly over the last 30 years (Yaskaskas, 2004). Therefore there is not the same expectation of an imminent death as in other life-limiting conditions; also death at an earlier age during adulthood is expected, whereas in conditions such as cancer, death may be expected in the short term, or parents do not know whether or not to expect an early death.

Also, as mentioned earlier, children with diabetes can expect an average of 20 years less of life expectancy, so parents in both groups may have some similar concerns.

Studies relating to other chronic illnesses or conditions that were excluded were those where the child had a potential terminal diagnosis within a short time period, where there was normally no requirement for daily treatment management procedures (such as for some sensory, motor or learning disabilities), and where the child had a cognitive impairment. Excluded conditions included deafness or blindness, cerebral palsy and spina bifida (where there may be no daily treatment requirements), epilepsy (where treatment is likely to only be oral medication), phenylketonuria (where treatment is only dietary), sickle cell anaemia (where no daily treatment is needed and acute exacerbations, if they occur, are only periodic) as well as any form of cancer (as this has a potentially terminal diagnosis). Although it is possible that some of this literature could be relevant to this study, these exclusion criteria were applied to strengthen the likelihood that the reviewed studies would be relevant to the current study.

2.3 ADJUSTMENT OF PARENTS OF CHILDREN WITH A CHRONIC ILLNESS (GENERAL), WITH ASTHMA OR DIABETES, JUVENILE ARTHRITIS OR CYSTIC FIBROSIS

2.3.1 Cross-sectional research where parent adjustment is the focus of the investigation

It has already been noted in Chapter 1 that previous research, for example Cadman et al's epidemiological study (1987), shows that parents of children with a chronic illness are at higher risk of experiencing mental health problems. However, the nature and possible causes or predictors of adjustment problems have not been widely investigated. A part of a literature review by Wallander and Varni (1998) that reported findings on parents' adjustment will be reviewed, together with some cross-sectional studies that met the inclusion criteria and specifically focused on parents' adjustment. Whilst most studies adopt a non-categorical or mixed approach, there are some examples of categorical research with children with diabetes, JRA and CF. Findings from the literature review will be discussed, followed by a discussion of the findings of the cross-sectional studies and implications for future research.

Review of literature review

Wallander and Varni (1998) reported that with the exception of two studies taking a longitudinal approach (Thompson et al., 1994 and Timko et al., 1992), maternal adjustment

was measured at only one point in time. Furthermore, only one childhood chronic illness group was included in the study samples (occasionally two), and these were normally from only one clinic. This group of studies used a range of self-report measures, showing that mothers' adjustment problems fell, on average, one standard deviation above the mean for the general population. It was reported that in the longitudinal study by Thompson et al. (1994) (including samples of parents of children with spina bifida or sickle cell disease), over the 19 months of the study, some mothers' adjustment was stable, whilst others' either improved or worsened. They conclude that further longitudinal studies are needed to highlight changes in mothers' adjustment over time. Wallander and Varni do not discuss why these individual differences might exist, why only mothers (not fathers) constituted the study participants, or whether findings differed across illness groups.

Wallander and Varni (1998) also found few studies investigating adjustment at a family systems level; they reported finding only one study on marital satisfaction (in couples whose child had cancer) (Dahlquist et al., 1996), which showed mothers' adjustment improved over a 20 month period, although fathers' did not. There were other gender differences in marital satisfaction over time and also in coping processes. Wallander and Varni also highlighted that there were some studies on family functioning using standardised family functioning measures, where one family member was a respondent (usually the mother). An exception to single-respondent research was a study by Northam et al. (1996), which found that different family members reported different experiences of family functioning over a 12-month period following a child's diagnosis of Type 1 diabetes, although there was no overall evidence of diminishing impact on family functioning over this period of time. Wallander and Varni argue that these studies are not very enlightening because the standard measures of family functioning are not able to reveal the meaning of the often confusing, disparate and complex study findings, and recommend more studies are carried out using direct observations of family interactions. The possible value of qualitative research in this area is not mentioned.

Wallander and Varni also report on study findings relating to risk and resistance factors for parents' adjustment, specifically illness-specific experiences and stressful life events. Studies on the former have been investigated as risk factors and include parents' experience at diagnosis, illness severity, visibility of the illness, and illness features such as effects on bladder or bowel function, cognitive or communicative impairments. Findings have been inconsistent, and these authors suggest that using frameworks to classify illnesses according to their features and also using inventories to estimate the illness burden might provide further precision to findings. Although Wallander and Varni report that some research has investigated specific risk factors of stressful life events (such as hospitalisation, loss of career

opportunities), they only mention ones that were conducted by Wallander and colleagues with regard to parents of children with physical disabilities. For example, a qualitative study by Wallander and Noojin (1995) involving interviews with mothers resulted in a list of 400 disability-related problem descriptions. Wallander and Varni did not elaborate on the relevance of these problem descriptions to parents of children with various chronic illnesses. They conclude their discussion of risk factors by noting that poorly explored areas include the impact on mothers' adjustment of the child's developmental stage, and experiences over the course of the illness.

The proposed model by Wallander and Varni (as outlined in their review) was used to classify research on resistance factors that relate to: stress processing, intrapersonal factors and social-ecological factors. Stress processing is a concept originating in Lazarus and Folkman's (1984) theory, and relates to appraisal of stressful events and coping responses. They report that a few studies have been undertaken on coping with illness-related stress, commonly finding that palliative coping methods are associated with poor maternal adjustment, whilst adaptive ones are associated with better adjustment. Cumulative stress has also been associated with higher maternal adjustment problems. They argue, on the basis of Lazarus and Folkman's theory, that future research should investigate parents' appraisals of illness-specific events.

With regard to intrapersonal factors, Wallander and Varni note that little attention has been given to explaining individual variation in parents' adjustment. All the reported research relates to Wallander and colleagues' studies on children with physical disabilities (primarily cerebral palsy and spina bifida). Although not specifically about chronic illness, it might be relevant to note that these studies showed that mothers' perceptions of their problem-solving ability increased the likelihood of their use of adaptive coping strategies, which were associated with better adjustment.

The last of the three resistance factors is social-ecological factors. Wallander and Varni claim that family support has generally been shown to be associated with maternal adjustment across different chronic illness groups. Also, they report that good maternal adjustment has typically been associated with low family conflict and an emphasis on control in the family relations. Specific studies are not described in detail in the review, with the exception of one by Wallander et al. (1989) on parents of children with spina bifida or cerebral palsy. This study found that 60% of the variance in maternal adjustment was explained by practical resources, social support network, child adjustment, service utilisation, family support and marital satisfaction, with the latter two being the best predictors. One further study supported

these findings (Barakat and Linney 1992). A further study of mothers and fathers of children with JRA (Timko et al., 1992) found that spousal dysfunction predicted both parents' adjustment one year later. Wallander and Varni argue that more research needs to be undertaken to help explain the social processes responsible for resilience of mothers of children with a chronic illness, including how they make use of health care services.

Overall, this review was helpful in highlighting some key areas of research focus in the past, although it largely centred on areas of particular interest with regard to the authors' conceptual model, so might have overlooked some important studies. Furthermore, they did not seem to differentiate between various chronic illnesses and physical disabilities (although acknowledging earlier in their paper that some illness-specific differences have sometimes been found to influence research findings), and they mentioned some but did not really discuss a number of other key deficits or omissions from this body of literature. These included the lack of consideration of fathers' adjustment, cross-cultural research and the need for more qualitative research to help reveal processes underlying the experience of adjustment.

Review of research studies

The following studies examine a range of variables that were hypothesised by researchers to be associated with maternal adjustment. These include illness-specific and demographic variables, as well as individual factors such as parents' stress appraisal. Some of the more recent research has focused on risk and resilience factors, to try to identify some of the reasons for individual differences in parents' adjustment. Some research presents models that predict direct relationships to parent adjustment as well as mediational processes, which can be helpful when attempting to explain individual differences.

Of the individual research studies on maternal or parents' adjustment, one of particular relevance to the question about the importance of illness-specific variables was a study by Gustafsson et al. (2002). In a sample of families of children with moderate to severe asthma, they examined the relationships between the child's disease severity (as measured by 4 levels of medication usage) and psychosocial problems experienced by different family members. They carried out correlation and cluster analyses of variables from a parent questionnaire and interview about problems in economy, work, contacts, leisure, health, knowledge, environment and family domains, from which they had derived a 'problem index'. Common areas of problems reported by parents were financial worries, decreased contacts with friends,

less vacations, cinemas and theatre going, physical and psychological exhaustion, sleep problems, helplessness, low flexibility and feelings of heavy responsibility. The severity of asthma was reported as being an important variable – high medication consumption was related to high perception of psychosocial problems. However, Gustafsson et al. make the assumption that high medication usage is a good indicator of ‘severe’ (and uncontrollable?) asthma, although in fact high medication use could be an indicator of good preventive self-care (as asthmatics generally take both preventive and reliever inhalers). Unfortunately, the methodology did not allow investigation of other explanations for why the child’s high medication use was associated with more psychosocial problems.

Another categorical study was undertaken by Thompson et al. (1992), investigating stress, coping, family functioning and adjustment of mothers of children with cystic fibrosis. The aim of the study was to investigate the contribution of mediational processes to maternal adjustment (defined as the degree of anxiety, depression and distress), after taking into account illness severity and demographic parameters (age, gender, SES). Interestingly, the illness and demographic parameters accounted for only 13-15% of the variance. Poor maternal adjustment was associated with daily stress and stress about illness tasks, lower efficacy, more use of palliative coping methods, low family supportiveness and high family conflict. In the multiple regression analysis, mediational processes accounted for a further 35-40% of the variance beyond that of illness severity and demographic parameters; the most important of these was appraisal of stress, particularly when related to daily hassles. This accounted for the largest increment in variance for both maternal anxiety and depression, and for more variance than stress associated with illness tasks. They comment on limitations of the findings, including the discovery that different measures of adjustment and parent distress tap different constructs, and they recommend that future researchers carry out structured clinical interviews to resolve this issue. An interesting aspect of these findings in the context of the present study is that specific illness-related tasks were not as important for adjustment as daily stressors in other aspects of parents’ life, suggesting these are important to investigate.

Lustig et al. (1996) examined a range of risk and protective factors in mothers of children with JRA which have been shown in other chronic illness research to influence maternal mental health and the impact on the family. These include characteristics of the child’s condition (including prognosis, biological and functional severity), environment or social context, family functioning, service use and stressful life events. In structured interviews, measures such as the Impact on Family (IOF, Stein and Reissman, 1980), the Psychological Symptom Index (PSI, Ilfeld, 1976) and illness parameters and context characteristics (such as

child age and gender) were administered. Backward multiple regression analyses revealed that mothers whose children were taking both steroidal and non-steroidal medications (indicators of greater illness severity) experienced higher psychological symptoms than those whose child took only non-steroidal or no medications. Fifty-three percent of these mothers scored in the 'high' range of psychological symptoms and where children experienced functional limitations in activities of daily living, parents' PSI scores were higher. Biological and functional illness severity accounted for almost 50% of the variance in maternal mental health. This adds to existing evidence that illness-specific features can influence parents' adjustment, which the authors suggest reflects the greater emotional and financial burden of caring for children with functional impairments. Lustig et al. went on to examine sets of mediational associations and found that the child's functional status predicted maternal mental health, partially mediated by maternal appraisal of the impact on the family.

Functional limitations of the chronically ill child were also hypothesised to be a predictor of maternal adjustment (as measured by psychological distress) in a study by Silver et al (1995). They were particularly interested in individual differences in maternal adjustment, and whether maternal psychological resources, self-esteem and efficacy have a 'buffering effect', reducing severity of the impact of the chronic stressor of functional limitations of the chronically ill child. These authors found that the mother's personal psychological resources (especially efficacy or perceived control), directly influenced the degree of mother's psychological distress, independent of stress, leading them to conclude that these personal resources are an important buffer against the chronic stressor of functional limitations. Additionally, a significant interaction between maternal efficacy and the child's functional status was found, and fewer symptoms of distress were reported by mothers who had a higher sense of self-worth and control over life events.

A non-categorical study was undertaken by Silver et al. (1998) also considered functional limitations among a range of other variables. They argued that the role of illness-related consequences for parent adjustment had been overlooked in the many studies that only considered the child's health status. Furthermore, they suggested that the use of 'checklists' to measure symptoms could mean that relevant illness consequences had been missed in previous studies. In an attempt to address this concern, they recruited 200 parents of healthy children and 200 parents of chronically ill children to their study from a larger inner city and national American survey sample. Children's illnesses were classified as having any of three features – functional limitations, reliance on compensatory mechanisms (e.g. regular insulin injections) and service use or need above routine care. They found that mothers and fathers of children with functional limitations had the most psychiatric symptoms (especially

mothers), whereas those with children having no functional limitations were not significantly different from control group parents. This is an interesting point, although it is unclear why these functional limitations had such an impact on parents' adjustment.

Canning et al. (1996) carried out a non-categorical study investigating factors that predicted the distress of parents (mostly mothers) of chronically ill children (with inflammatory bowel disease, diabetes, cystic fibrosis or cancer), as measured by the Brief Symptom Inventory, a 53-item checklist of psychiatric symptoms (Derogatis, 1992). Hierarchical multiple regression analyses were used to examine effects of sociodemographic variables, health status characteristics and perceived burden of caregiving on caregivers' distress; this study was unusual outside adult chronic illness research in investigating perceived caretaking burden. Also, sociodemographic variables had been included in previous research as co-variables rather than predictors. Significant predictors were found to be the caregivers' perception (but not physician's perception) of the burden of the illness, low income and a female child. It was suggested that parents might view a female child as being more vulnerable, and this could lead to greater anxiety. In contrast to most other studies, the child's functional status was not a significant predictor of parent distress or adjustment. A possible explanation is that a proportion of the children in this sample were reported to have been diagnosed within the last 2 months, so the child's functional restrictions may not yet have been determined. However, the authors did not state the mean and standard deviation of years since diagnosis in their sample, so this suggestion is tentative.

Dodgson et al. (2000) investigated a relatively new area in child / family chronic illness research, that of the impact of uncertainty in chronic illnesses on parents' mental health. They examined the relationship between uncertainty in young children's chronic illness and distress of mothers and fathers, in particular the significance of predictability of symptoms degree of certainty in life expectancy for parents' distress, as measured by the Impact on Family Scale (IOF) (Stein and Riessman, 1980), which measures family/social disruption, financial burden, role strain, emotional strain and mastery. MANCOVA analyses (with levels of life expectancy and symptom predictability as covariates) showed that both mothers and fathers of children with intermittently unpredictable symptoms reported more distress than where the child's symptoms were more predictable. In particular, greater family/social disruption, emotional strain and financial burden were significantly higher for mothers, whilst family/social disruption was significant for fathers.

A mixed categorical / non-categorical approach to investigating parental adjustment was undertaken by Hentinen and Kyngäs (1998). They conducted a postal questionnaire survey of

parents of children with one of three chronic illnesses (diabetes, asthma and JRA). Factor analyses revealed a 4-factor solution, characterising poor adaptation (conflicts in the family, sorrow and fear for child's disease and future) and positive adaptation (acceptance of the situation, nearness and social relationships). Whilst they were looking for relationships between parental adjustment and child chronic illness in general, some disease-specific differences were noted in relation to frequencies of these characteristics. Parents of children with diabetes experienced family conflicts and care-taking difficulties significantly more frequently than in the asthma or rheumatoid arthritis groups, and parents of children with rheumatoid arthritis experienced more fear and sorrow about their child's disease and future. Parents of children with asthma had the most positive adaptation characteristics. However, the severity or other features of the children's asthma in this sample is not specified, and this could influence the findings.

A more recent non-categorical study was undertaken by Dewey and Crawford (2007), examining the correlates of maternal and paternal adjustment to chronic illness. They were particularly interested to investigate variables within the Wallander and Varni (1998) model, and also whether the adjustment of fathers and mothers would be different. Unusually for this area of research, they included a control group as well as separate groups of parents of children with non-life-limiting and life-limiting conditions. Following administration of many of the measures used in other studies of this type, hierarchical regression analyses revealed some similarities and some differences in correlates of maternal and paternal adjustment. Interestingly, this study did not find significant differences between adjustment of parents of children with a chronic illness and those of healthy children using these measures, nor were there significant differences between the two chronic illness groups. Important predictors of poor maternal adjustment were lower family cohesion and lower social support, whereas for fathers these were lower family cohesion, higher family life stressors (with items asking about areas of conflict between a couple, having a family member lose or quit a job, or parents separating or divorcing) and higher scores on coping by understanding the medical situation. The models accounted for 58.1% and 58% of the variance in maternal and paternal adjustment respectively. These findings were consistent with other research that showed that mothers reported more difficulties than fathers, but it was interesting to note that fathers' adjustment was more affected by total family life stressors and by coping by asking questions of professionals and other parents. The authors do not offer an explanation for these findings, although this highlights the importance of investigating fathers' adjustment.

The concept of stress appraisal has also been considered in a study by Manuel (2001), in a sample of mothers of children with JRA. In her survey, Manuel found that when mothers experienced high levels of illness-related and daily hassles stress, they experienced more psychological symptoms, after accounting for disease severity and functional status. However, maternal education and appraisal of stress moderated this effect. In other words, a more positive appraisal of stressors was related to fewer psychological symptoms, suggesting that both maternal education and positive appraisal of stress may contribute to more positive adjustment.

In summary, the literature review by Wallander and Varni (1998) and the studies focusing specifically on maternal or parental adjustment have shown that in general, parents of children with a chronic illness experience adjustment problems more often than parents in the general population. Contrary findings might relate to differences between studies in measures used, hypotheses that lead to different multiple regression models, illness features and consequences, demographic variables (such as child age) and / or timing of data collection (at different times during the illness course). There is also some inconsistency in research findings on whether or not parents' adjustment varies with the type of childhood illness. Reasons for this could include within-illness differences in illness severity across different samples with the same condition (an issue highlighted by findings of Gustafsson et al., 2002), and / or because of some of the points mentioned above that could lead to disparate findings (such as lack of consideration of demographic variables or timing of data collection within the illness course). Research investigating risk and resilience (such as by Silver et al., 1995) could also account for individual variations in adjustment, including the buffering effect of efficacy and control, and personal resources.

Another finding from the above studies is that different family members may experience adjustment differently. Mothers' adjustment seems to be best predicted by variables such as low family conflict, family cohesion, marital satisfaction, family support and social support. The limited evidence on predictors of fathers' adjustment indicates some differences, including higher family life stressors and a coping strategy of seeking information about the illness. The latter seems to be in contrast to findings in general that adaptive coping strategies are more effective than palliative strategies in promoting good adjustment, but it's possible that if fathers' efforts to find information are less effective, this is more distressing for them. The study by Canning et al. (1996) also suggests that doctors might not perceive the parents' burden as being as great as that perceived by the parent; this points to the benefit of accessing multiple respondents in future studies.

Finally, the difficulty in comparing study findings should be mentioned. In general, there was poor description of sample characteristics that might influence findings (such as time since diagnosis, illness severity or controllability - particularly asthma, where there are widely varying experiences of symptoms, age of the children, whether parents are single or in a relationship, socio-economic status and cultural group), and only two studies had a control group (Silver et al., 1998, Dewey and Crawford, 2007), and these were not matched for child age or other variables.

In summary, a number of recommendations for future research have been offered by these authors, including the plea for more longitudinal studies to help elicit causal processes in adjustment and how this changes over time (Silver et al., 1995; Wallander and Varni, 1998), a greater need for systems-level explanations (Wallander and Varni, 1998), more research on fathers' experience of adjustment (Dewey and Crawford, 2007), on the impact of child development on parents' adjustment and on stress appraisal (Wallander and Varni, 1998) and on important factors that differentiate between the effects on adjustment of different illnesses and their features (Gustafsson et al., 1992; Silver et al., 1998). Whilst there is some suggestion that models (and in particular that proposed by Wallander and Varni) may help to bring some coherence to this literature, there is also the risk that important factors relevant to parents' adjustment may be missed by approaching studies with preconceived notions about the experience of adjustment and related processes, which are largely based on general theories.

2.3.2 Cross-sectional research on child adjustment where parent adjustment is included as a correlate

There are some examples of cross-sectional studies that met the inclusion criteria for this section of the review, where parent adjustment variables were included. In these studies, they were viewed as correlates of child adjustment, where the latter was the focus of interest. Some of these will be included as illustration, as they are not very illuminating since the parents' adjustment is not usually discussed. However, they serve to emphasise how much of the research on child chronic illness has not given much consideration to parent adjustment. Typically, standard measures of depression and anxiety are used.

A relatively common measure of this type is the Brief symptom inventory (BSI/ Derogatis and Spencer, 1982), which is a brief form of the SCL-90-R (Derogatis, 1983), with depression and anxiety sub-scales. Mullins et al. (1995) explain that T scores can range from 30-80 on

this measure. In a study by Mullins et al. (1995), depression and anxiety measures in mothers of CF and diabetes groups had mean scores and standard deviations on the BSI of between 55 and 55.9, and 8-9.7 respectively. In another study by Lopez et al. (2008) of mothers and adolescents with asthma and diabetes, mothers' scores on this measure were reported as $M=53.39$, $s.d.=9.68$ (asthma group) and $M=55.01$, $s.d. 9.44$ (diabetes group). Therefore, there seems to be some consistency in scores on this measure across illness groups. Unfortunately, in neither of these studies do the authors state which cut-off score is considered clinically significant, nor do they discuss these findings in particular – only in relation to child adjustment outcomes.

For example, in the study by Mullins et al. (1995), although they note that maternal anxiety and depression scores were similar for mothers in the two illness groups, maternal depression was found to be significantly correlated with child depression in the diabetes group but not the CF group. They suggest that this might relate to timing of diagnosis, which is earlier in the CF group; families of children with CF 'grow up' with the illness demands and prognosis, whereas those with diabetes do not.

Another measure sometimes used is the Beck Depression Inventory (Beck et al., 1988), used for example in a study by Cuneo and Schiaffino (2002) of adjustment of children with JRA. In this study, mothers and fathers' scores were reported for the mother as $M=6.87$, $s.d.=6.49$, and father, M of BDI= 4.36 , $s.d. 4.94$. According to Beck et al. (1996), these scores would represent a minimal level of depression, although Cuneo and Schiaffino (2002) did not specifically discuss this. Although in this study, the Adult self-perception profile (Messner and Harter, 1986) was also used, which measures parents' self-worth (possible range = 5-20), the significance of the scores for the mother as $M=15.76$, $s.d. 3.11$ and father as $M=15.99$, $s.d. 2.71$ were not discussed. Therefore, it is not clear how these relate to any cut-off score of clinical significance.

In a categorical study on children with diabetes and their mothers, Jaser et al. (2008) investigated the mediators between maternal and child depression. Maternal depression was measured using as self-report instrument, the CES-D (Centre for Epidemiologic Depression Scale) (Radloff, 1977). Clinically significant depression (as measured by a cutoff score of 16/20) was found in 22% of the mothers in this sample, with the population prevalence being 6.6% for adults. This corresponds with similar research on the prevalence of depression in this population of mothers.

A more useful study in this group of cross-sectional studies was by Chisholm (2003) on the adjustment of adolescents with diabetes. A diabetes adjustment questionnaire (completed by both adolescents and their mothers) was administered to both adolescents and their mothers. Differences were found between those mothers whose child had 'psychological problems' and those whose child did not. In particular, where a child was classed as having psychological problems, mothers were more significantly likely to report having to keep an eye on their child's activities, worry about their child when away at school or with friends or when not at home on time, and worries about the future. They were also more likely to report not being able to work because of the child's illness, needing to attend to their child's needs at all times of the day and give them lots of extra attention when unwell, having reduced self-confidence, more conflicts with their husband, more restrictions on family activities, not eating meals together and believing life was more difficult for the child's siblings.

These examples illustrate some recognition in this type of research of the importance of parent adjustment for child adjustment, but the studies only use standardised general measures of adjustment (for example of anxiety and depression measured by the BDI) and do not really offer any helpful insights into why parents might have higher or lower scores, except in relation to the child's adjustment.

2.3.3 Longitudinal research investigating parent adjustment over time

The review by Wallander and Varni (1998) identified only two longitudinal studies (Timko et al., 1992; Thompson et al., 1994) that specifically investigated parents' adjustment over time, and these related to specific illnesses, neither of which was diabetes or asthma. However, two studies published at around the same time and not included in the review were by Frank et al. (1998) and Chaney et al. (1997). Frank et al. investigated adjustment over time in parents of children with juvenile rheumatoid arthritis or diabetes, and Chaney et al. on diabetes.

Timko et al. (1992) investigated adjustment of mothers and fathers of children with JRA at two time periods, 1 year apart. Predictors of coping were investigated as well. It was found that both mothers and fathers' functioning was stable over this period with regard to depression, personal strain, social activities and mastery. However, the time period may have been too short to observe significant changes. The average age of the children was 9.4 years, a common age of diagnosis (Symmons et al, 1996); however, the authors did not make reference to when the children had been diagnosed. This could have helped to identify how parental adjustment in the period soon after diagnosis might be different a year later.

Thompson et al.'s sample in one of their two studies was mothers of children and adolescents with cystic fibrosis (CF); the second study recruited mothers of children with sickle cell disease. The mean scores of maternal distress reduced over this time period for the CF group, but were not significantly changed for the sickle cell group, and there was moderate stability in maternal adjustment classifications for both groups. A factor contributing to the limited changes over time could be that the time period between the two measurements was only 9-19 months in the CF study and 8-16 months in the sickle cell sample. Furthermore, in both samples the children would have been diagnosed some time previously. The average age of the children in the CF sample was 12.16 years; since CF is normally diagnosed in infancy, most if not all of these parents would have been coping with a chronically ill child for over a decade. In the sickle cell disease sample, the children's average age was similar (12.1 years); the disease can be diagnosed prenatally or in early childhood. Omission of an assessment of the early years post-diagnosis is unlikely to reflect an accurate account of the extent of changes in maternal adjustment over the course of the illness.

This issue was addressed by Frank et al. (1998), who undertook a longitudinal study of patterns of family adaptation over time where a child had JRA or diabetes, which included the period soon after diagnosis. Measurements of child behavioural and physical functioning, parent psychological functioning and coping, and family adaptability and cohesion were taken at diagnosis, 6, 12 and 18 months. Four cluster solutions were discovered of adaptation over time. Of the two disease groups, families of children with juvenile rheumatoid arthritis had the worst adaptation, whilst families with younger children were more adaptive over time. More longitudinal studies of this type need to be undertaken, and the reasons for better or worse trajectories of adaptation that are associated with different disease states and stages of development should be determined. Furthermore, qualitative studies such as the current study, may help to further reveal the reasons for such differences.

A study by Chaney et al. (1997) investigated mothers and fathers' adjustment as well as transactional patterns over the space of one year of child, mother and father adjustment where the child had diabetes. The timing since child diagnosis varied from within one month of diagnosis to over 12 years post-diagnosis. Parent adjustment was measured using the SCL-90-R (Derogatis, 1993), which measures anxiety, depression and anger. Most parents' adjustment was stable over this period and mothers' and fathers' adjustment was similar. This contradicts previous research which has shown the mother to have higher scores on maladjustment. However, these authors argue that this is because the measures that were used in other studies only included assessment of depression, which tends to be higher in women.

2.3.4 Review of research on parent experiences related to adjustment – qualitative studies

A number of studies in this general topic area were identified, mostly published in nursing journals. The majority of these described experiences of mothers and / or fathers where the child had cancer, disabilities or congenital conditions such as cardiac defects. These were not selected for review as they did not meet the inclusion criteria for the selected illnesses. However, a number were found on parents' adjustment experiences in general, and where parents had children with diabetes. No qualitative studies were identified on the experiences of parents of children with asthma. The following studies offer some useful insights, and show an emerging interest in qualitative research approaches on this topic.

Experiences of parents of children with a range of chronic illnesses

In a qualitative study using thematic analysis, Gannoni and Shute (2010) investigated parents' and children's perspectives on what helped or hindered child adaptation to chronic illness; some children in the sample had diabetes. Focus groups and interviews were used to explore the challenges and processes parents and children felt to be important in adapting to the illness. Eleven themes were identified including six that related to the impact of the illness on aspects of their lives, and the remainder related to the meaning of the illness, stress-processing, social support, future concerns and psychosocial interventions. Both illness-specific and illness-general findings were reported. The reported results mainly described common emotions and experiences (such as shock at diagnosis, disruptive effects on family activities, financial difficulties and communication difficulties with health professionals). However, positive, adaptive emotions were reported such as increasing confidence, and pride in the child's self-management abilities. Parents also reported that they used methods to strengthen the family's functionality such as sharing care with a partner.

The perspectives of fathers was considered by Hovey (2005), who aimed to identify concerns and coping strategies of fathers of children with cancer, cystic fibrosis and juvenile rheumatoid arthritis through asking parents to complete two subscales of the Family Perception Inventory (Hymovich, 1992). Among fathers' concerns were worries about their child's future, being able to do activities together as a family, having leisure time as a family and having time to be intimate with their partners. The fathers perceived that their wives

were also concerned about their child's future, but additionally thought that their wives were concerned about feeling worn out and the responsibility of caring.

Experiences of parents of children with juvenile rheumatoid / idiopathic arthritis

Sallfors and Hallberg (2003) undertook a study using grounded theory exploring mothers' and fathers' experience of living with a child with juvenile arthritis. Key themes arising from the analysis related to 'parental vigilance' (with related emotions of anxiety, parental protection and watchfulness), 'emotional challenges' (with related sub-themes of uncertain parenting, communication with others, and concerns about the unknown), and 'continual adjustment' (with related sub-themes of living in the here and now, looking for information and striving for relief and strength).

Britton and Moore (2002), presented findings of a qualitative study investigating experiences of each core family member and grandparents about the experience of having a child with juvenile rheumatoid arthritis. Most mothers reported having to refocus their lives from being a parent to becoming a carer, because of having to incorporate extra work from prescribed care. They reported experiencing feelings of grief, isolation and helplessness, and of feeling unsupported by some health professionals. Helplessness was sometimes infused with anger, for example about their inability to relieve the child's pain. Few fathers participated in this study but of those who were interviewed, most asserted that their lives had been greatly changed by the child's illness, and reported experiencing significant distress (although apparently unspoken, as the mothers had not perceived this). The diagnosis was shocking, as the fathers had not realised this was an illness that children could acquire, and this made acceptance difficult. Those fathers who participated in care were more likely to describe changes to their own lives and the emotional and practical burden of care. Fathers tended to worry more about the child's future, whereas mothers worried more about present challenges (such as peer relationships).

A further qualitative study in relation to experiences of caring for a child with JRA related to those of fathers (MacNeill, 2004). In this grounded theory study, McNeill interviewed 22 fathers about their experiences of parenting a child with JRA. Fathers expressed perceptions that chronic illness was a catalyst for identifying new values and experiencing personal growth, and were generally optimistic and motivated to be a source of strength for their partner.

Experiences of parents of children with diabetes

Six qualitative studies described and analysed the initial and later experiences of parents of children with Type 1 diabetes (Hatton et al., 1995; Sullivan-Bolyai et al., 2003; Sullivan-Bolyai et al., 2006; Wennick and Hallstrom, 2006; Marshall et al., 2009; Edmonds-Myles et al., 2010). Most were phenomenological studies, where the researchers interviewed parents, sometimes children with diabetes and other family members as well. In two cases, parents and children were interviewed separately and together (Marshall et al., 2009; Edmonds-Myles et al., 2010). A few other qualitative studies are discussed in the next section, which relate to parents' grief responses.

Marshall et al. (2009) used 'conversational interviews' in a UK study to elicit experiences of 10 children, 10 mothers and 1 father about living with diabetes. Thematic analysis revealed four main themes that were common to parents and children: transition (e.g. relating to times of the child's development when more responsibility was taken), attachment (realignment of relationships), loss, and meaning (e.g. finding the treatment disruptive and intrusive). 'Normal' was a central unifying theme across these four themes, i.e. the child wanted to be normal, and the parent and child were reminded of this when striving for normality.

Intrusiveness in daily lives as a result of the illness and its management was also reported in a qualitative study by Sullivan-Bolyai et al. (2003) of American mothers of children under age 4 with Type 1 diabetes. Mothers described the management strategy of 'constant vigilance', and how the child's care was a burden on their mental and physical health; this was found especially for those mothers whose resources were limited. Parents reported feeling isolated, initial feelings of incompetence (particularly when their child had hypoglycaemia), although with time their skills improved. Parents also discussed difficulties with access to child care and babysitting.

Hatton et al. (1995) also interviewed American mothers of very young children (under age 3), and in common with findings of Sullivan-Bolyai et al. (2003), they described parents' feelings of tremendous responsibility, and that it consumed their lives. Particular stress was related to the lability of the child's condition, having to administer painful treatment and related demands and fears, multiple losses in the child and family life, social isolation, not trusting others to care for the child, and concerns about the future. Parents described their experiences in three phases – around the time of diagnosis, secondly, when they were learning to assume full responsibility and finally, when they were feeling more in control and able to incorporate

the diabetes into their lives. Different stressors, responses and coping strategies characterised each phase.

The experiences of 12 Swedish families of older children aged 7-14 years were explored by Wennick and Hallström (2006) within the first three months of diagnosis with diabetes. All family members were interviewed individually (including siblings); themes identified related to learning processes. These were 'learning about the inevitable' (facing signs of the illness prior to diagnosis, feelings of powerlessness and feeling confidence) and 'learning about the extent' (family alterations, uncertainty and restrictions). Family members found that new situations or contexts sometimes triggered moves between 'learning the inevitable' to 'learning about the extent'.

The experiences of fathers of children with diabetes under the age of 10 were explored in a descriptive qualitative study by Sullivan-Bolyai et al. (2006). These fathers were all involved in the child's care, and described their initial responses, how they learned about and carried out the care, and the strategies they used in daily treatment management. There was an overarching theme of 'From sadness to action', incorporating the 6 categories of shock and awe (around diagnosis), learning the care, staying in the loop (keeping up with learning new skills, tasks and responsibilities), partnership with the other parent, active participation, and the mantra, 'child first, diabetes second'. The authors suggest that fathers would particularly benefit from practising tasks related to treatment, to improve their confidence when taking sole responsibility for the child.

An interesting descriptive study by Edmonds-Myles et al. (2010) explored the influence of low income, race and ethnicity on the experience of patient-parent dyads where the child with diabetes was aged 10-18 years and had been diagnosed for at least one year. The sample included participants with Hispanic, African American or white heritage. It was not reported whether any of the parents were fathers. Half of the parent participants from the Hispanic and African American families were single parents, whilst there were none in the group of white participants. Themes common to all three groups were noted (such as initial responses of anxiety, sadness and isolation) but there were some cultural differences, with the Hispanic and African American participants placing much more emphasis on cultural, financial difficulties and family factors (including the difficulties of single parenthood). Hispanic families perceived the diabetes as more of a burden, expressed more worry, were more preoccupied with the disease and reported more concerns about relationships with health professionals than did other groups. Families of white heritage were more likely to report sources of support than in the other two groups, who disproportionately used support groups.

This body of evidence offers some useful insights into this topic, particularly about positive aspects of the experience, emotional responses and challenges, feelings relating to the illness (such as worry about the present or future) and also what was helpful or less helpful for parents' adjustment. It is also interesting to observe that fathers and mothers often had different responses, emphasising the importance of accessing multiple respondents' views. There is quite a lot of consistency in the findings of the qualitative research with parents of children with diabetes and their families, particularly concerning experiences at diagnosis, the learning processes involved in caring, and the burden of the illness. However, it is notable that overall, most of this research in this area centres on a limited number of illnesses, and it can be seen from the findings reported above that experiences vary both within and between illness groups and in different cultural groups. More research needs to be undertaken, including more varying samples from different chronic illness groups, in order to explore illness-specific and other influences on parents' experiences.

2.3.5. Research on some specific emotional responses of parents: post-traumatic stress and chronic sorrow

The body of literature to be reviewed below includes qualitative research and reviews that relate to two specific aspects of parent emotional responses that could be considered relevant to parent adjustment; these are the constructs of post-traumatic stress and chronic sorrow.

Post Traumatic Stress Disorder

Cabizuca et al. (2009) undertook a meta-analysis of the prevalence of post-traumatic stress disorder (PTSD) in parents of children with a chronic illness or undergoing invasive procedures in comparison with health comparison groups. They found that the pooled PTSD prevalence from these studies was 19.6% in mothers, 11.6% in fathers, and 22.8% in general, which was found to be significantly greater than the prevalence of PTSD in the general population. This highlights an aspect of parents' response not typically identified, but which emphasises the importance of supportive care (particularly at times of extreme stress).

Chronic sorrow

An emerging concept in some of the nursing literature relating to chronic illness is that of chronic sorrow. This relates to the grief responses of parents in the months and years following a diagnosis of a child's chronic illness. In a literature review on chronic sorrow in

parents of children with Type 1 diabetes, Lowes and Lyne (2000) describe how these parents often initially experience a grief reaction similar to that experienced following bereavement. However, rather than eventually reaching a final stage of acceptance as predicted by 'time-bound' theorists such as Kubler-Ross (1970) where initial grief culminates in acceptance, some parents may experience chronic sorrow. Lowes and Lyne (2000) cite a concept analysis of chronic sorrow by Teel (1991) which describes chronic sorrow as being characterised by recurring feelings of sadness amongst other periods of neutrality, satisfaction and happiness. Therefore, parents experiencing chronic sorrow have adapted to the experience of the child's chronic illness, but have not accepted it.

This review by Lowes and Lyne (2000) concludes that whilst most parents adjust to their child's diagnosis, there is good evidence that some continue to experience periodic grief responses for many years following diagnosis. In some cases, parents conceal their grief and in fact may be suffering from ongoing depression. Lowes and Lyne hypothesise that the relentless, painful and intrusive nature of treatment management in Type 1 diabetes, with the ever-present reminders of short and long-term consequences of not following this regimen, evokes continual reminders of their loss. This finding could contribute to explaining why clinical levels of depression are more frequently found in this population of parents than in general. Furthermore, it suggests that other ways of assessing parents' adjustment may be needed, because particularly for those parents who conceal their grief, they may superficially have adjusted to the illness and on 'good days' may report good adjustment on standard measures, although may in fact be experiencing unrecognised underlying depression or other psychopathology.

In a longitudinal study, Lowes et al. (2005) explored grief and eventual adaptation responses of parents through 3 interviews – within 10 days of diagnosis, then at 4 and 12 months. Parents' responses were interpreted within a framework of psychosocial transition, characterised by parents trying to make sense of their situations and revising their assumptions about their world.

Bowes et al. (2009) undertook a qualitative study using in-depth interviews to investigate the experiences of 17 parents (mothers and fathers) of children with Type 1 diabetes 7-10 years after diagnosis. They note that most previous qualitative studies have investigated parents' initial or early experiences post-diagnosis, so this is a relatively unexplored research question. Using a theoretical framework of grief, loss, adaptation and change to analyse data, they report finding that although respondents had adapted to the practical aspects of diabetes management, all but one parent had not accepted the diagnosis and reported experiencing

resurgences of grief at critical points in their child's development or during re-hospitalisation episodes. Mothers in particular often became upset during interviews when describing the period of diagnosis, suggesting the continued emotional saliency of this experience. Anger and guilt relating to the child's diagnosis were also expressed by both fathers and mothers. The authors conclude that most parents in this population of parents will probably never achieve 'closure' or true acceptance of their child's condition, and that this should be recognised by health professionals who need to offer longer-term emotional support.

Ajesh et al. (2006), in a phenomenological study exploring the experiences of working parents of children with chronic illnesses (such as developmental and learning disabilities, and life-limiting conditions), reported similar findings of parents expressing chronic grief, especially at diagnosis. Although these acute feelings resolved, they resurfaced during specific encounters, such as in medical situations where insensitive health professions or others triggered periodic renewals of grief. Not being listened to or understood by health professionals was a key concern. Parents also talked about the burden of caring, financial issues and concerns in their working life.

These studies again emphasise the value of qualitative studies in helping to understand the parents' experience of adjusting to caring for a child with a chronic illness. In particular, these findings demonstrate that the parents' emotional responses at a time of diagnosis might not be short-lived as perhaps might be expected by some clinicians and researchers, and their needs might not be easily identified through standard measures that tend to show improvement in adjustment over time. They also point to possible implications for practitioners, particularly in the area of communication and support. Further research with families from different childhood chronic illness groups would be beneficial.

2.4 PARENTS' QUALITY OF LIFE

Quality of Life is a useful construct to consider within the body of literature on parent adjustment, because it extends beyond the idea of parent adjustment as an absence of psychopathology, which has been the focus in much of the earlier research on adjustment. Also, rather than measuring mental health as lists of psychiatric symptoms, depression or anxiety, quality of life measures tend to focus on emotional wellbeing, daily functioning and satisfaction with different aspects of life. This recognises that parents' quality of life may be affected by having a child with a chronic illness, even if they do not exhibit symptoms leading

to a diagnosis of a psychiatric disorder (Goldbeck, 2006). Nevertheless, this type of research in relation to parents' quality of life is not well developed, with only one study being identified on the quality of life of parents with Type 1 diabetes (Faulkner, 1998). Just two studies were mixed categorical / non-categorical (Lawoko and Soares, 2003; Goldbeck, 2006) although there has been a growing number of studies with parents of children with asthma (Osman, 2001; Villa, 2003; Halterman, 2004; Walker et al., 2008; Al-Akour, 2009; Dean et al., 2009; Annett et al., 2010).

Quality of life was defined by Gill and Feinstein (1994, p. 619) as, '*A uniquely personal perception, denoting the way that individual patients feel about their health status and/or non-medical aspects of their lives.*' Goldbeck (2006, p. 1122), in her study of the quality of life of parents of children with a chronic illness proposed a modification of this definition, to express the concept of the quality of life of parents as: '*A uniquely personal perception, denoting the way an individual **parent** feels about **the health status of their child** and/or non-medical aspects of their lives.*' In previous work, Goldbeck and her colleagues based at University Clinic, Ulm, Germany, developed and validated a measure of this construct, the UQOLI (Ulm Quality of Life Inventory). This appears to be the only non illness-specific measure of parents' quality of life, and is published in German. The study by Lawoko et al. (2003) used a Swedish QoL measure for adults. The UQOLI includes an overall measure of QoL, as well as on separate subscales of physical and daily functioning, satisfaction with support from the family, emotional stability, self-development and well-being.

Mixed categorical / non-categorical (incorporating diabetes) and diabetes-specific studies

The mixed categorical / non-categorical study by Goldbeck (2006) investigated the quality of life of mothers and fathers at two time periods (1-2 weeks after diagnosis and after 2-3 months) in two groups: those whose child had either been diagnosed with cancer or with the chronic illness of diabetes or epilepsy. Goldbeck found that the QoL of parents in both groups, overall and on all subscales (except for satisfaction with the family situation) was significantly lower at both time periods in comparison with the QoL of parents without a chronically ill child. It was suggested that this could be accounted for by the observation in other research that families often become more cohesive at times of stress. However, in the cancer group the QoL was worse (lower) than in the diabetes / epilepsy group both at Time 1 (near diagnosis) and Time 2 (after 2-3 months). Low scores on subscales at Time 1 were still

evident at Time 2 in both groups, except that in the diabetes / epilepsy group, physical and daily functioning was now similar to norms. These findings indicate that parents' QoL continues to be affected some months after diagnosis, particularly for parents of children with cancer.

In a study of the QoL of children and adolescents with diabetes and their parents, Faulkner (1998) found that in response to a QoL questionnaire, parents reported that the burden of their child's diabetes significantly affected their life satisfaction, and this was found to be associated with the child's metabolic control. Greater life satisfaction was reported by parents of the younger children in the sample and by married parents. Parents' greatest worry was about the child's risk of complications from diabetes.

Asthma-specific studies

As mentioned earlier, there seems to be an increasing interest in parents' quality of life with regard to childhood asthma. This may be facilitated by the development of illness-specific, validated measures such as the Pediatric Caregiver's Quality of Life Questionnaire (Juniper et al., 1996), developed for parents of children with asthma. This includes two subscales, one about the impact of the child's asthma on parents' daily activities and the others about their worries about the child, evaluated over the previous week (Osman et al., 2001). The following table summarises these findings:

Author(s) and date	Research aim	Sample	Quality of Life or other outcome measures	Findings
Osman et al., 2001 (UK)	Validate PACQL-Q for parents of preschool children with wheezing illness; evaluate correspondence of QOL scores with symptom data over 3 months	Mothers of preschool children with wheezing illness (aged 0.8-6 years)	PACQLQ, frequency of respiratory symptoms over 3 months.	QOL correlated with symptom frequency. At entry and follow-up, younger and more economically disadvantaged mothers had lower QOL scores. PACQLQ may be used for parents of children of this age.

Author(s) and date	Research aim	Sample	Quality of Life or other outcome measures	Findings
Villa et al., 2003 (France)	Investigate relationship of adolescent emotional and behavioural problems to quality of life of adolescents with asthma and parent, using path analysis	Adolescents with asthma, aged 12-19; 25% had poorly controlled asthma. Severity ranged from mild persistent to severe persistent	PACQLQ (and other child measures)	Best fit path analysis showed parent and adolescent QOL influenced adolescent emotional and behavioural problems. Adolescent internalising behaviour affected quality of life of both parent and child; adolescent externalising behaviour had moderate effect on parent QOL. Illness severity not significant.
Halterman et al., 2004 (USA)	Investigate relationship of sociodemographic factors and child asthma severity on parent QOL	Urban children 3-7 years, with mild persistent to severe asthma (severity monitored monthly over 1 year)	PACQLQ, administered twice (baseline and 1 year later)	All measures of asthma severity correlated with parent QOL.
Al-Akour and Khader, 2009 (Jordan)	Investigated the QOL of parents (mothers and fathers) of children with asthma	Children with asthma	PACQLQ (Pediatric Asthma Caregivers' QoL (using domains on activity limitations and emotional function) – measured over one week.	Overall, moderately positive QOL; more limitations in domain of activity limitations than emotional function. Highest QOL in parents of older children, in rural areas, with mild asthma.

Author(s) and date	Research aim	Sample	Quality of Life or other outcome measures	Findings
Walker et al., 2008 (USA)	Examine relationship between asthma severity, parents' missed days of work, asthma education and quality of life.	Parents of school aged rural children (grades K-4, i.e. approximately 5-10 years), asthma severity ranged from mild intermittent to severe persistent.	PACQLQ subscales: (EQOL): emotional domain, and (AQOL): activity domain	Parent QOL significantly correlated with number of missed days of work. EQOL and AQO correlated with child asthma severity.
Dean et al., 2009 (USA) N.B. Large scale study	To investigate absenteeism from work (for parents) and school (for children) over a 6 month period of parents of children with asthma.	Parents of children aged 12-17. 1,990 children had controlled asthma and 1,038 children had uncontrolled asthma	PACQLQ data from 1,543 caregivers; absenteeism data over 6 months (available from 2,535 caregivers)	31% of caregivers of children with uncontrolled asthma and 16% where child had controlled asthma reported lost working days. Uncontrolled asthma associated with reduced PACQLQ, generally and in subscales.
Annett et al., 2010 (USA)	To test two conceptual models of associations between constructs predicting (1) QoL in children with asthma and (2) QoL in their parents	217 families of children with asthma; children aged 10-18 (asthma severity or controllability not described)	Medical attitudes questionnaire (no attributed author)	Parent perception of family functioning predicted their perception of child psychological functioning. Together with long term asthma control, child psychological functioning predicted parent QoL.

These findings show that in most studies, parents' QoL correlates with the child's asthma symptoms, particularly when uncontrolled. This is a more precise and possibly more helpful definition than is sometimes seen in literature about adjustment on asthma, which refers to severity as defined by medication use (e.g. Gustafsson et al., 2002), because of the possible stress for parents of not being able to control their child's symptoms. Another finding of interest is that child psychological functioning is a frequent predictor or correlate of parents' quality of life. This reinforces findings of literature on adjustment (as discussed earlier), showing an association between child and parent adjustment.

2.5 FAMILY ADJUSTMENT OR FUNCTIONING

Family functioning is a different concept from adjustment, but it is argued that it has important relationships with it. Good family functioning is likely to be reflective of good parental adjustment and good parental adjustment may contribute to good family functioning.

Literature investigating family functioning was considered for this review because researchers offered systems level explanations (which acknowledge reciprocal effects). In these studies, there were normally outcome measures related to family functioning. Unfortunately, as with the measures of parent adjustment, eleven different measures of family functioning were used in the relatively small number of studies, reflecting a varied understanding of family functioning.

2.5.1 Studies taking a categorical approach

Five categorical studies were found that investigated family adjustment or functioning. These related to family or dyadic functioning in families where the child had diabetes, cystic fibrosis or asthma.

Hanson et al. (1992) investigated the degree to which family relations and behaviours were related to diabetic adolescents' (11-22 years) adaptation (as predicted by Social Learning Theory) or whether the influence was indirect, through factors such as marital satisfaction and parent-child conflict (as predicted by family systems theory). They also investigated relationships between illness-specific and general family relations. As with many other studies, for the first aim, they tested models using hierarchical regression to investigate predictors of child adaptation, and for the second, they carried out zero order correlational

analyses. Results from the latter revealed that illness-specific support was significantly correlated with general family adaptability (flexibility) and general family affection; also, illness-specific non-support was significantly associated with general family conflict. However, it is unclear whether family adaptability and affection was caused by illness-specific support or whether families that are adaptable are more likely to seek support.

A different approach was taken by Borrow et al. (1985), whose analysis was of mother-child dyads. Firstly, they examined the relationship between mother-daughter interaction and adolescent adherence to their medical regime, using measures of family functioning. Secondly, they investigated whether mother-daughter interaction in discussions about feelings and problems was associated with the adolescent's concerns about diabetes and their adherence. Mothers of poorly adhering adolescents were more confrontive and more risk taking in their interaction style. In contrast, mothers of good adherers were more speculative with their daughters (i.e. asked questions, offered tentative solutions). Such evidence is useful in identifying potentially maladaptive mother-daughter relationships that could be detrimental to family functioning. However, in common with the previous study, it is not clear whether poorly adhering adolescents made mothers behave in a more confrontive way, or vice versa.

A similar study has been undertaken more recently by Berg et al. (2007), with reference to transactional processes between adolescents with diabetes and their mothers. They investigated the relationship between adolescents' involvement in their mothers' coping efforts and its association with maternal adjustment (as well as the reciprocal effect). A significant challenge for parents during adolescence is achieving a collaborative approach to treatment management, where the adolescent takes a developmentally appropriate level of responsibility, whilst still maintaining good adherence to treatment. Berg et al. argue that if an adolescent appraises the mother as being available for collaboration, they will not view the parent as either under-involved or intrusive, and adolescent adjustment will be better. Similarly, it was predicted that if the mother appraises the child as actively engaged in managing treatment, then collaborative transactions would result, and these would be supportive of mutual coping. To investigate these hypotheses, maternal and child depression and maternal mood were measured using standardised tools, and participants were interviewed about diabetes stressors and coping responses. It was found that if mothers appraised that their child was uninvolved in the mother's coping efforts, then less positive maternal emotion and more depressive symptoms were reported, particularly where the adolescents were older. Also, where participants appraised efforts as being collaborative (especially in the case of daughters), this was associated with more positive maternal emotion.

Dyadic relationships were also studied by Quittner et al. (1998), in this case in families with a child with CF, and using the concept of role strain in couples as an indicator of adjustment. Parents of children with CF experienced significantly greater role strain than comparison parents, had more conflict over child rearing, more child-care tasks, greater role division discrepancy from ideal, and fewer positive interactions. Wives in the CF group had more parenting stress, and therefore marital role strain in all areas. Couples with a child with CF had less time for social and recreational activities and women were considered in an 'at risk' category with regard to depression. For women, role frustration and role conflict was associated with marital adjustment, and parenting stress and role frustration was related to depression. For men, conflict and daily exchange of affection was associated with marital adjustment and parenting stress, and role conflict was correlated with depression. More research of this type needs to be undertaken to highlight how spousal relationships are affected by a child's chronic illness.

In a cross-cultural study of Icelandic and American families, Svavarsdottir et al. (2005) examined whether parents' sense of coherence and family hardiness was related to family and caregiving demands and the severity of a child's asthma, and also whether these would predict family adaptation. Svavarsdottir et al. found that in both cultural groups, parents' perceptions of family coherence and hardiness predicted family adaptation. However, Icelandic mothers viewed their family's adaptation more favourably. Also for fathers in both cultures, family demands predicted adaptation. The effect of family demands on adaptation was moderated by both parents' perception of family coherence.

This group of findings show that a range of factors may influence family or dyadic functioning where a child has a chronic illness, although there are too few studies from which to draw strong conclusions. However, there are indications that it would be advantageous for future research to investigate the significance of both external (such as illness-specific support) and internal factors (such as perception of family coherence and hardiness and parents' role negotiations) for optimal dyadic or family functioning, and in particular to highlight any illness-specific variables.

2.5.2 Studies of family functioning taking a non-categorical or mixed approach

Lavigne and Faier-Routman (1993), in their second meta-analytic review, reported that marital or family adjustment and family support / cohesion were significantly correlated with child maladjustment in many of the studies. Similarly, Drotar (1997) found in all but 4 of the reviewed studies that at least one measure of parent or family functioning was significantly related to child adjustment. Measures of child adjustment usually included those of

internalising and externalising behaviour, each of these being associated with different family functioning characteristics.

For example, Hamlett et al. (1992) found that children with diabetes or asthma who exhibited externalising behaviour were more likely to come from families with poor cohesion and high conflict. Children with internalising behaviour had families who reported less adequate social support. Interestingly, when disease groups were combined, Hamlett et al. found no differences in general family functioning between families of well children and those with a chronically ill child. This may again show how a non-categorical approach can obscure important disease-related variables influencing family functioning.

Klennert et al. (1997) examined predictors of positive family adaptation and quality of life. They investigated how families of children with asthma manage the illness, which is argued to be relevant to adjustment and quality of life. They noted that there was no instrument to assess the functioning of the entire family system with regard to asthma management. They developed a comprehensive, semi-structured interview called the Family Asthma Management System Scale (FAMSS) to assess quality of life of families' management of their children's asthma in general as well as in specific domains. In addition, they measured the severity of the children's asthma. The validity of the FAMSS was assessed by relating the FAMSS score to the child's concurrent asthma functional impairment. This accounted for a significant amount of the variance, independent of the severity of the child's asthma, which was related to the child's asthma-related functional impairment. Both combined, the FAMSS score and the asthma severity score accounted for 29% of variance of the child's reported functional impairment, indicating that those two factors contribute to a child's daily health status and functioning.

In a mixed categorical / non-categorical study by Holden et al. (1996), differences in maternal and child adjustment and family functioning were measured across two child diseases, asthma and diabetes. Using a 2x2 MANOVA, with child's disease and gender as factors, and dependent variables that included measures of maternal coping and family functioning, the significant main effects were that families with asthma were more adaptable, and family cohesion was higher in both groups when the child was a girl. Maternal coping was not significantly different as a function of either age or gender. However, when using general child and family variables (e.g. demographic data, numbers of children with the condition) as covariates, there was a main effect of age for family cohesion, which were negatively related, i.e. families of younger child had better cohesion, and vice versa. It was thus possible to conclude that disease type and gender affect family functioning, but not maternal coping.

In a Finnish study, Taanila et al. (1999) investigated how mothers and fathers experienced family cohesiveness after diagnosis where the child had diabetes, an intellectual or physical disability. They argue that although family cohesiveness often increases after diagnosis, this is not necessarily good for parent adjustment if this is characterised by enmeshment. Enmeshment refers to a pattern of family functioning where there is an almost exclusive focus on the ill child, which may result in exclusion of external social relationships, work or leisure activities (Minuchin, 1974, cited in Taanila, 1999). Interviews and a questionnaire (designed by the authors) were used to assess family cohesiveness, the importance for the family of social support, social activities, working life and leisure. Statistical data were not presented, apart from percentages of parents responding in particular ways. Families from all illness groups reported an increase in family cohesiveness around the time of diagnosis and after, although less so in the diabetes group. In general, the importance of social, working life and leisure did not decrease, despite increased family cohesion. Mothers in particular valued social support from grandparents and friends. Some mothers reported that the importance of work had reduced, whilst some fathers said the importance had increased. Parents, especially in the groups for children with disabilities, reported a decrease in leisure time.

An unusual study was undertaken by Williams et al. (2002) examining variables previously shown to be associated with differences in maternal 'mood', sibling 'mood', sibling self-esteem and behaviour in families where a child had CF, spina bifida, cancer, diabetes or developmental disabilities. The authors used structural equation modelling to examine interrelationships among individual or demographic variables and a measure of family cohesion which the authors had previously shown to be associated with these aspects of sibling and parent mental health or development. It is surprising that individual differences in the chronically ill / disabled child were not included in the equation modelling (i.e. only the disease groups), as there can be quite significant within-disease variability. Although this was an initial test of this model, it is interesting to note that family cohesion and sibling age, knowledge about and attitude towards the illness were important factors influencing maternal mood.

Knafl and Zoeller (2000) undertook a mixed methods study comparing mothers' and fathers' experiences of having a child with a chronic illness (diabetes, asthma or juvenile rheumatoid arthritis). In addition to in-depth interviews, the authors administered a range of scales including family functioning and mood. Findings from all the data collection methods revealed that mothers and fathers have a high degree of agreement in views about the impact of the illness, how it affected family life and the family functioning. Themes from the

qualitative analysis identified child identity (viewed as normal / not normal), treatment management (confident / not confident), illness as foreground or focus to family life (illness focus / not focus), parental mutuality (agreement on how care should be managed or not) and transformative experience (parent is now different person or not); most parents had views that downplayed the impact of the illness. Although there was a high level of agreement, mothers were more likely to have a more negative perspective about the child's identity (not being normal), more likely to lack confidence in managing the illness, and describe themselves as having been transformed by the experience. The authors point out that the mothers in other research studies experience more grief, which is not dissimilar in that there is a more negative outlook on the experience.

Finally, Dewey and Crawford (2007) investigated correlates of maternal and paternal adjustment to having a child with a chronic illness (cystic fibrosis, muscular dystrophy, asthma, diabetes, and healthy controls). Hierarchical regression analyses were used to predict maternal and paternal adjustment from the variables of social support, coping strategies, family life stress, and family adaptability and cohesion. Maternal adjustment was related to lower family cohesion and lower social support and paternal adjustment by lower family cohesion, high total family life events and high scores on coping by understanding the medical situation. It is interesting to note that although family cohesion was important for mothers' and fathers' adjustment, the other predictors were different for each parent group.

2.6. DISCUSSION

Analysis of overall findings and implications for future research

This review has shown that the literature in this area is very disparate and somewhat lacks coherence. There are many reasons for this, including an apparent lack of theoretical direction to studies, although there have been attempts to do so (such as Wallander and Varni's 1998 model). However, this model primarily relates to child adjustment, and was originally based on existing theory on stress and coping, perhaps limiting additional insights that might have been gained through a more inductive approach to devising a model. The lack of theoretical perspectives shown in most studies possibly contributed to the lack of clarity about the concept of adjustment (or adaptation); this might account for the very wide range of selected variables identified within research aims. Many measures of adjustment were used, including a range of general psychological measures of depression and anxiety as well as researcher-designed tools that included many different variables. To name a selection of these: difficulties in social or work life, feelings of responsibility, acceptance of the illness, psychological resources, self esteem, self-efficacy, self-worth, mood, social support and

coping strategies. Furthermore, measures developed by researchers have not always been adequately validated. Also, as many of the studies are correlational, it is difficult to identify causal processes (although recent efforts using structural equation modelling and path analysis may add rigour to this body of research).

A second issue is that those authors that adopt a non-categorical approach do not necessarily consider what is similar about the illness groups considered that is relevant to adjustment. An exception was the study by Silver et al. (1998), who examined the role in adjustment of illness consequences of functional limitations, compensatory mechanisms (i.e. treatment management) and service use or need above routine care. Other consequences perhaps could include the degree to which the illness is life-limiting (i.e. poor prognosis, so life will be shortened), visibility of the illness (e.g. eczema) and the variability of the illness (i.e. it comes and goes, or is consistent).

Although there is value in taking such a non-categorical approach, there is evidence from this review that on its own, this is insufficient. Even when focusing on general features (like physical functioning), important unique illness-specific features are not recognised. An example is the severity and / or controllability of the illness, in which (for example in asthma) there is significant intra-illness variability. Therefore, more studies that adopt mixed categorical / non-categorical designs would be beneficial.

Other areas needing further exploration include how gender, age at diagnosis, length of illness, child age and stage of development, child beliefs, social class and culture influence parent adjustment, although a few studies have included one or more of these points in the analyses (e.g. Holden et al., 1997; Frank, 1998). This body of research would also benefit from the more consistent inclusion of comparison groups of children unaffected by chronic illness. Additional longitudinal studies, particularly those that last more than a year, would be very helpful in order to identify when families might need additional support. Whilst it is encouraging to see more research including fathers, this group continues to be under-represented and some of the reasons for mixed results could be explored further. It could be that where measures have not revealed adjustment problems in fathers, measures are not specific enough for them (i.e. fathers' problems may be obscured by measures used).

An encouraging trend in recent research has been on the experiences of parents in a range of aspects of their lives (for example in the quality of life research). This increases understanding of families needs and offers scope for holistic care, as well as tools for measuring outcomes of care. Systems-level and qualitative research studies also offer a wider understanding but are still lacking in this area. Whilst it is encouraging to note that

qualitative studies are being published in relation to some areas of parents' experience, these seem to be concentrated around a few childhood illness groups, and there are very few non-categorical or mixed studies that highlight similarities and differences between experiences of parents whose children have different illnesses. This is an important consideration for future researchers.

Summary and implications for the present study

In the context of the present research study, it is useful to highlight findings of particular significance for parents of children with chronic illness, and in relation to those whose child has asthma and diabetes. The research reviewed has offered very good evidence that the diagnosis and management of a child's chronic illness can significantly impact on parents' and families lives, and that parents' adjustment changes over time. It has also shown that there is much individual variability in parents' adjustment, with some parents showing much resilience in the face of significant challenges. Many of the quantitative studies have proposed and tested predictive models incorporating factors that might account for individual variability, including social-ecological, individual and illness-related factors. However, these models have been derived through deductive rather than inductive processes, presupposing that important variables have been selected for testing. Through starting from the perspective of parents' own experiences rather than theoretical predictions, as is generally the case in qualitative research, it is possible to gain a more in-depth appreciation of what is important for parents' adjustment.

Qualitative research to date has begun to achieve this aim, through helping to identify how some parents experience adjustment, for example (in the case of a diagnosis of diabetes) as movement from initial distress and grief at diagnosis, to learning to manage the illness, and possibly coming to terms with the illness. In the present study, it will be valuable to further examine the experience of parents through these times of transition, and also to explore the experiences of parents of children with asthma, with whom equivalent qualitative research has not been undertaken. It will also be valuable to further explore the extent to which these two groups of parents experience adjustment in similar or different ways. Finally, as most of the qualitative research to date is descriptive, a methodology that will facilitate theory development will be able to offer unique insights of significance for both theory and practice.

CHAPTER 3 – STUDY DESIGN

3.1 AIM AND OBJECTIVES OF THE RESEARCH STUDY

Aim:

The aim of this research is to describe and analyse data concerning the individual and family life of parents of children with diabetes or asthma. Emphasis is placed on data that have significance for parental adjustment so that new theoretical perspectives about parental adjustment will be developed as an outcome of the analyses.

Objectives:

Some of the following objectives and associated research questions were present at the start of the study, but others arose during the data collection and analysis phase, which is consistent with grounded theory methodology (Charmaz, 2003).

- 1) Examine similarities and differences in parents' perceptions of the impact of the illness on the child's emotional and social life; consider how these perceptions influence parents' practical and emotional responses.
- 2) Examine similarities and differences in illness and treatment features and the illness management experiences of child and parent; consider the significance of these for the child's and parent's adjustment.
- 3) Examine the parents' experience of the effects of the child's illness and its management over time, as the years since diagnosis increase and as their child develops and matures.
- 4) Describe and examine parents' experiences since their child's diagnosis, in relation to their personal and family life, employment and leisure.
- 5) Ask questions about the data to explain similarities and differences in parental coping and adjustment, and how and why this changes.

- 6) Discuss the findings and theoretical model, and the implications for future clinical practice and theory development.
- 7) Examine the psychological concept of adjustment and discuss its meaning in relation to parents of children with Type 1 diabetes and asthma.
- 8) Identify which parent behaviours may be reflective of better or less good adjustment, and any predictors of adjustment.

3.2 OVERVIEW OF THE METHODOLOGICAL APPROACH: QUALITATIVE, USING GROUNDED THEORY

3.2.1 Rationale for selection of a qualitative methodology

In the literature review of this thesis, it was shown that most research on parental adjustment has been descriptive, experimental or quasi-experimental. It was shown that there have been few qualitative studies on this topic, mostly in the nursing literature. These have focused on psychological responses of parents of children with a chronic illness, and have tended to explore coping rather than adjustment (e.g. Hovey, 2003; 2005). Where parental adjustment has been assessed in empirical studies, it has often been part of an investigation of the variables influencing adjustment of children with a chronic illness, rather than parental adjustment *per se*. The literature review also demonstrated that many researchers have focused on assessing parental *maladjustment* (rather than both positive and negative adjustment), through using measures of psychiatric morbidity such as the Psychiatric Symptom Index (PSI) or the GSI (Global Symptom Index), a section of the SCL-90-R.

Therefore, future methods need to enable investigation of the whole experience of parents of children with chronic illness and what contributes to their adjustment (both positive and negative). It is argued that a qualitative research design is best able to achieve this, and so would be appropriate for the aim and research objectives of this study. Qualitative research is concerned with understanding the meanings that people attach to their personal and social worlds. In-depth insights may be gained that may not emerge through most quantitative designs. In topic areas that are under-researched such as this one, qualitative studies may highlight new issues and relationships between factors that have not been identified through research that tests specific hypotheses.

Ritchie and Lewis (2003) outline how qualitative research can reveal, in fine detail, the experience of a study population, unpacking issues and revealing relationships. They explain that it can be undertaken for descriptive, exploratory, explanatory, evaluative and / or generative (theoretical or practical) purposes. Qualitative methods would serve well the objectives of this study, as achieving those outlined above requires descriptive and exploratory methods, as well as those supporting the generation of explanations. Whilst there is no specific evaluative purpose of this study, some of the answers to questions in objectives 3, 4 and 8 could point to needed changes in health services, as these may highlight service needs. Objectives 6 and 7 have generative purposes, to develop new conceptions or understandings on the topic, and make practice recommendations. A grounded theory approach was considered to be most suitable for achieving these ends, as explained in the next section.

3.2.2 An explanation of grounded theory

Grounded theory is a form of qualitative enquiry first described by Glaser and Strauss (1967), and since applied extensively in social sciences and other disciplines. The main goal of grounded theory is to generate theory from empirical data that have been collected, coded and analysed through qualitative methods. Grounded theorists differ from each other in their emphasis on the key elements of the methodology (Rennie and Fergus, 2006); these authors note for example that Glaser (1978; 1992) has persisted with his original view that theory generation should be the main focus of the methodology, whereas other theorists such as Strauss and Corbin (1990; 1994), Corbin (2008) and Charmaz (2000) emphasise the interpretative aspects.

Grounded theory data analysis procedures generally involve techniques such as constant comparison of coded data, leading to development of categories and sub-categories, from which theory is generated (McCann and Clark, 2003). Whilst grounded theory researchers and theorists are likely to agree with these general methodological principles, there are differences with regard to their underlying beliefs (paradigms) and with the specific methods (techniques, procedures) adopted, as alluded to above. Some of these methods are influenced by the paradigm that has been selected (Charmaz, 2000); even so, it is probably not possible to be a purist, a view that has been captured by Rennie and Fergus (2006, p. 484):

'Users are encouraged to be naïve about the phenomenon of interest while being encouraged to bring sensitizing concepts to it. They are encouraged to be descriptive in the early stages of the analysis and conceptually abstract in the later stages. They are given the impression that social phenomena are external to the research and awaiting discovery, while being told that these phenomena are to be formulated creatively. They are encouraged to believe that with the correct procedures they will be able to access social phenomena grounded in reality, while being advised that the returns from the grounding will vary depending on the interest of the particular analyst.'

Whilst being aware of these tensions, it is still important to establish the central paradigm adopted in this study. It is widely recognised that attention to philosophical issues is likely to enhance research practice; being transparent about assumptions and methodological decisions connected with these means the research is more open to scrutiny (Snape and Spencer, 2003). Therefore, the next sections will examine paradigms (and associated beliefs) that are typically adopted in grounded theory approaches. In addition, there will be a justification for the central paradigm adopted in this study, and the associated ontological, epistemological and methodological positions.

3.2.3 An examination of paradigms in qualitative research

Lincoln and Guba (2000) argue that a researcher's paradigm includes four key concepts: ethics (axiology), epistemology, ontology and methodology. *Axiology* is bracketed next to ethics because it is about beliefs concerning what is intrinsically valuable in the world in terms of knowledge, and this influences researchers' moral stance. *Epistemology* describes beliefs about the nature of knowledge and how it can be acquired, whilst *ontology* relates to beliefs about the nature of individual and social worlds and what can be known about these, whilst *methodology* relates to the choice of ways of gaining knowledge about the world.

Lincoln and Guba (2000) propose that there are five key paradigms, as presented in the table below, which includes brief definitions of key terms.

Table 3.1: A Comparison of Beliefs associated with Five Paradigms
[The table has been modified from Lincoln and Guba (2000, p.168)]

Issue	Positivism	Post-positivism	Critical theory	Constructivism	Participatory
Axiology (Ethics)	‘Propositional knowing about the world is an end in itself, is intrinsically valuable’ (p. 172)	‘Propositional knowing about the world is an end in itself, is intrinsically valuable’ (p. 172)	‘Propositional transactional knowing is instrumentally valuable as a means to social emancipation, which as an end in itself, is intrinsically valuable’. (p. 172)	‘Propositional, transactional knowing is instrumentally valuable as a means to social emancipation, which as an end in itself, is intrinsically valuable’. (p. 172)	‘Propositional, transactional knowing is instrumentally valuable as a means to social emancipation, which as an end in itself, is intrinsically valuable’. (p. 172)
Ontology	naïve realism: ‘real’ reality but apprehendable	critical realism: ‘real’ reality but only imperfectly and probabilistically apprehended	historical realism: virtual reality shaped by social, political, cultural forces over time	relativism: local and specific	participative reality: subjective-objective reality, cocreated by mind and given cosmos.
Epistemology	dualist / objectivist; findings true	modified dualist/objectivist; critical tradition/community; findings probably true	transactional/subjectivist; value-mediated findings	transactional/subjectivist; created findings	critical subjectivity in participatory transaction with cosmos; extended epistemology of experiential, propositional and practical knowing; cocreated findings.
Methodology	<i>dualist / objectivist;</i> findings true methods chiefly quantitative methods, e.g. experimental and quasi-experimental.	<i>modified dualist/objectivist</i> critical tradition/community; findings probably true methods chiefly quantitative methods e.g. field research	<i>dialogic</i> (understanding through transactional discourse)/ <i>dialectic</i> (creating transformation or synthesis of perspectives) methods naturalistic, qualitative	<i>dialectic /hermeneutic</i> (uncovering embedded meaning through words and text) methods naturalistic, qualitative	political participation in collaborative action inquiry; primacy of the practical use of language grounded in shared experiential context.

Axiology

Table 3.1 shows that there is a key difference in views between positivist / post-positive and the other perspectives about the value of knowledge derived from qualitative research. Lincoln and Guba (2000) claim that no ‘blurring’ is possible between such starkly different axiological beliefs. As such, they argue that this absolutely militates against blending methods associated with these extreme views, or each accepting findings from the others’ studies. This seems quite an extreme view. It is unclear why these two views of the value of knowledge would be considered incompatible. Is it not possible to view knowledge in itself as intrinsically valuable, as well as to value the outcome for social emancipation? This is in fact my own view, that both have value and are not mutually exclusive. If researchers acknowledge the value of each, there should be the potential for both acceptability of different methods and findings across paradigms.

Ontology

Snape and Spencer (2003) explain that three ‘pure’ philosophical stances exist about what there is to know about the world. These are realism, materialism and idealism (relativism); one of the key areas of contention is about whether or not there is one external reality, and if there are multiple realities, how these are constructed. Realists claim that there is an external reality that exists apart from individuals’ beliefs or understandings about it; people interpret the world in different ways that may or may not reflect the one external reality. Materialists believe that only material features of the world exist independently, but otherwise have similar views to realists. Idealists (relativists) claim that reality is socially constructed, so that there are many different realities and no external reality that can be known or measured. Idealism (relativism) is therefore most different from positivism, whilst realism is most congruent with it.

Few researchers take such purist views, and variations that integrate aspects of different perspectives may be seen, one being ‘subtle realism’, first described by Hammersley (1992). This view accepts that social phenomena exist independently of people’s representations of them, but proposes that accessibility to these representations is only gained through obtaining individuals’ or groups’ perspectives. This version of realism sits most comfortably with those positivist or post-positivist researchers who aim, through qualitative research, to develop theoretical and practical insights that are widely applicable.

This ontology is likely to be more consistent with beliefs of researchers who have been trained in experimental methodologies. For example, medical researchers Mays and Pope (2000) discuss how beliefs about ontology have significance for acceptability of qualitative research in medical science, particularly as the criteria for assessing research quality varies with different ontological perspectives. Part of this concern probably relates to scepticism from practitioners who are trained as scientists in empirical methods. However, Mays and Pope argue that if the same criteria of validity and relevance can be applied to research from both experimental and qualitative research based on subtle realism, this is likely to enhance the understanding and acceptance of qualitative research in medical sciences.

Authors such as Morse et al. (2002) and Lincoln and Guba (2000) adopt a different stance from Mays and Pope. The latter claim that (1) some ontological perspectives (i.e. non-realist) require different measures of quality than for experimental research, making findings less acceptable to medical practitioners and that (2) this means that an ontology of subtle realism should underpin medically-related research.

Regarding the first point, Morse et al. (2002) explain that the debate about whether different ontological views require different measures of quality has led to confusion in the field and a plethora of different quality criteria, which has not helped the acceptability of qualitative research in mainstream science. They convincingly argue (p.14) for a return to pre-1980s terms of validity and reliability:

'We challenge the prevailing notion that the danger of using the generic term 'validity' is that a particular method, for example ethnography, will be derailed from its philosophical underpinnings (Hammersley, 1992). Our argument is based on the premise that the concepts of reliability and validity as overarching constructs can be appropriately used in all scientific paradigms, because, as Kvale (1989) states, to validate is to investigate, to check, to question and to theorise. All these activities are integral components of qualitative inquiry that insure rigor. Whether quantitative or qualitative methods are used, rigor is a desired goal that is met through specific verification strategies. While different strategies are used for each paradigm, the term validity is the most pertinent term for these processes.'

Acceptance of this view refutes a key concern about the relevance of epistemologies in qualitative research for quality evaluation. Regarding the second point, Lincoln and Guba (2000), who have published widely on this topic, disagree that dissonance in ontological beliefs needs to be a barrier to acceptability of kinds of evidence from different paradigms or for employing mixed methods that are guided by different paradigms.

The ontological view most congruent with writers' perspective is a combination of relativism / idealism and subtle realism. Whilst it is accepted that people's view of the world is socially constructed (indeed, co-constructed), it is also considered that some aspects of social phenomena exist independently of people's representations of them. For example political systems exist, although people's interpretations and representations about them differ, with the development of these perspectives being intimately related to their social experiences. Furthermore, it is considered that there is likely to be some commonality within these co-constructed perceptions of the world, where individuals and groups share experiences (e.g. of a child with a chronic illness). These shared and individual perspectives, as argued by subtle realists, may be accessed through interactions with both groups and individuals. It is considered that this composite ontological view is most consistent with a constructivist paradigm.

Epistemology

Schwandt (2000) outlines three epistemological stances for qualitative enquiry that reflect different views about what should be the focus of research and what methods should be used to undertake it. These views are interpretivism (reflecting a dualist / *objectivist* stance), hermeneutics and social constructionism (reflecting *subjectivist* or transactional stance).

The aim of *interpretivism* is to understand and accurately construct people's subjective meanings that underlie actions, and to do so in an objective way (i.e. *objectivist*). It is recognised that a similar behaviour might have different meanings for different people. In order to get at this meaning, the researcher must interpret the behaviour, for example through empathic identification, analysing the system of meanings expressed through participants' language, or by using tools such as reflexivity to analyse how individuals' internal life world is constituted. However, it is important that the researcher 'objectifies' or remains personally external to the interpretations.

Hermeneutics differs from interpretivism in various ways, including beliefs about how one is able to access human meanings. Proponents believe that meaning is negotiated mutually by investigator and participant rather than constructed or simply discovered by the interpreter. This is because it is believed that human action is not an object 'out there', independent of its interpretation. Hermeneutics holds that understanding *is* interpretation. Schwandt (2000, p.196) describes understanding as 'a kind of practical experience in and of the world that, in part, constitutes the kinds of persons that we are in the world. Understanding is 'lived' or existential.' The hermeneutic circle (Geertz, 1988, cited in Schwandt, 2000) is used as a

method to understand these meanings. It involves a continuous switching between focusing on the part (e.g. sentences) and whole (e.g. human desires) to appreciate meanings. The researcher is not objective, but appreciates that his or her values, beliefs and personal history influence interpretations; these should be recognised and altered where these disable the researchers' ability to understand others. Therefore, it is *subjectivist* or *transactional*.

Schwandt (2000) outlines a final view, *social constructionism* (a term used in sociology), which he notes is akin to constructivism in psychology. In this view, people don't just describe or discover knowledge, but also construct it. They develop conceptual models or frameworks through which the world is described and explained. Within their social contexts, people draw upon shared understanding, values, cultural practices and language to build these frameworks. According to Denzin and Lincoln (2000), constructivists generally accept that respondent and researcher co-create understandings, and that naturalistic methodologies are used in investigations.

This epistemology is closest to the views of the author of this thesis. For example, in interview scenarios, questions may be asked by an interviewer about issues that participants have never thought deeply about. The interview questions tend to be chosen to encourage the participant to reflect further about such themes, so in some sense the interviewer is contributing to the development of a participant's conceptual framework, and *vice versa*. This epistemology is not inconsistent with a composite ontology of relativism / subtle realism, which reflects the view, as discussed earlier, that to gain knowledge and understanding, one needs to access individuals' and groups' representations of reality. Both these epistemological and ontological views sit comfortably within an overall constructivist paradigm, which would seem appropriate for this study.

Methodology

As briefly discussed earlier, choice of methodology is influenced, but not entirely determined by a research paradigm. Table 3.1 above shows that for the paradigm of constructivism, naturalistic enquiry is appropriate and would typically have a dialectic or hermeneutic methodology. Grounded theory would fall in the camp of the dialectic position, because researchers wish to see beyond the ordinary surface level of the data to develop new understandings (Strauss and Corbin, 1994).

A further consideration in choice of methodology is the aim of the research, as this will encompass a view on which kinds of data are needed. Ritchie (2003) suggests that data

collection strategies fall in one or two categories – those that access naturally-occurring data only and / or ones accessing generated (new) data. She suggests that different methods are appropriate for each purpose. For example, those that focus on the collection of naturally occurring data may include observation, documentary analysis, discourse analysis or conversational analysis. On the other hand, data generation requires approaches such as biographical methods, interviews or focus group discussions. The latter group of methods enable participants and researchers to reflect upon other perspectives and draw comparisons, and this is necessary for theory generation, an aim of this research study.

3.2.4 Summary of paradigm position and methodology adopted

In this study, a constructivist position seemed most appropriate, based on the above analysis. The constructivist paradigm is consistent with the views expressed in the previous section, i.e. a composite ontological view of relativism / subtle realism, an epistemological view that findings will largely be transactional, subjective and created, and that the methodology will be dialectic / hermeneutic (indicating that meanings will be uncovered through analysis of text). It is recognised that the paradigm influences the overall method adopted, as explained by Charmaz (2000), and is discussed below.

Charmaz (2000) notes that the constructivist paradigm is often adopted by grounded theory researchers although others, such as Glaser and Strauss (1967), are more objectivist in orientation. She considers herself as a constructivist, and makes a case for the advantages of adopting this paradigm. She points out the following key differences between constructivist and objectivist grounded theory, and how these factors help to define the methodology:

Table 3.2: A Comparison of Objectivist and Constructivist Grounded Theory Paradigms (from Charmaz, 2000)

Views	Objectivist Grounded Theory Position	Constructivist Grounded Theory Position
Origin of data	Data reflecting an external reality are collected through observation, interaction and analysis	Data are created through observation, interaction with participants and analysis
Research context	The interaction is framed by the researcher, including controls	Researcher and participants frame interactions and share meaning
Researcher contribution to data	The viewer is separate from what is viewed	The viewer is part of what is viewed

Views	Objectivist Grounded Theory Position	Constructivist Grounded Theory Position
Analytic process	Specific procedures are followed that are systematically applied and are reproducible	What is analysed is shaped by the viewer
Views about causality	Causality may be determined	Causality is suggestive and incomplete – open to refinement
Theoretical outcomes	True, testable hypotheses may be developed, leading to verifiable theory with future predictive power	Defines conditional statements that seek to interpret how participants construct their realities, but these are not generalisable truths

Charmaz elaborates on the advantages of a constructivist paradigm, with regard to the section in Table 3.2 above that relates to the analytic process. She argues that in a constructivist approach, the kind of conceptual level of coding used may be more likely to elicit rich data, because there is a deeper exploration of participants' views and values. Furthermore, whilst coding, constructivists will seek more to understand underlying assumptions rather than primarily stick closely to overt data.

Charmaz makes another point concerning the research context mentioned in Table 3.2. The researcher may also have the kind of relationship with a participant that does not focus primarily on gathering facts, which enables interactions to achieve greater depth. In contrast, Charmaz argues that objectivists tend to over-use terms, categories and conceptual maps, which can overly preoccupy them, distancing them further from the participants' experience.

However, as Table 3.2 demonstrates, adopting a constructivist version of grounded theory means that there would be less direction by the researcher and less specific procedures, making the process less visible to external observers. This might be viewed as important according to some quality assessment criteria. However, it is argued that provided one accurately describes and is explicit about the basis of decisions taken at each stage of the research process, the possible impact of this limitation may be minimised.

The following section describes the actual method used for sampling, determining study sites, data collection and analysis; it will be noted that the method has not adhered precisely to those used by any particular grounded theory researcher such as Charmaz (2000). In this

sense, it has accorded with the view of Glaser and Strauss (1967), viz that grounded theory may be more helpfully viewed as a methodology rather than strictly adhering to a prescribed set of grounded theory techniques and procedures. However, principles of grounded theory method have been used, namely in relation to coding (i.e. descriptive moving to analytical), the exploration of relationships within data (including possible influences on parent adjustment), and the intention to develop a theoretical model proposing explanations of variations in parent adjustment.

3.3 QUALITATIVE METHODS DESIGN

The following description explains the process of study site selection and process of purposive sampling. All but two participants were recruited from hospital clinics. The data collection process involved interviewing 18 parents and one grandparent of 16 children with asthma, and 22 parents of 16 children with diabetes. Participants were interviewed in the location of their choice. This section also explains the necessary amendments to the original recruitment strategy and a description of the study sample.

3.3.1 Data Collection Methods: Study sites, sampling, interviewing

3.3.1.1 Study sites, sources of data and sample

3.3.1.1.1 Background to choice of study sites

Hospital clinics were selected as study sites for a number of reasons. Firstly, the parent groups could be accessed because of their attendance at clinic with the child; usually all patients with the particular illnesses attended clinic on one day of the week. It would therefore be possible to predict the day of the week and location to attend for the recruitment process. Secondly, as discussed in the following section, the asthmatic children attending clinic were more severely affected than many asthmatic children in the general population who rarely had symptoms and may have experienced minimal impact on their lives due to the illness. Therefore, influences of the child's asthma on parental adjustment would be more able to be identified in a clinic population. Thirdly, the process of ethical approval would have been much more complex if participants had been accessed via Primary Care Trusts, as this would have meant submitting ethical approval applications to multiple sites and a greater amount of travelling to different sites.

3.3.1.1.2 Description of study sites

The main study site was a district general hospital that held paediatric respiratory and diabetes clinics, as well as in-patient services. This was a regional centre for both medical specialities. A secondary site was a paediatric diabetes clinic at a nearby district general hospital. As the main study site was a regional centre for paediatric diabetes and respiratory care, attendees often lived at a distance. In contrast, most attendees at the secondary site lived locally.

Most children from both illness groups attended clinic every three months. This was the case for all diabetic children, although asthmatic children whose health showed improvement over time (particularly if they were well controlled on their medication and had not had a hospital admission in the last year) were discharged from the clinic and followed up instead by their GP. Therefore, those asthmatic children attending the clinic had more severe or less well controlled asthma, and many had had at least one emergency hospital admission within the last year. This was not the case with the diabetes group, where few children were admitted to hospital. Two parents of children with asthma were not hospital clinic attendees. They had heard about the study through word of mouth, contacted the researcher and volunteered to be interviewed.

Parents were asked where they would like the interview to be conducted, and their requests were complied with. The majority of parents were interviewed in their own homes, although some were interviewed at clinic, and one at her workplace. The participants' homes were dispersed throughout Oxfordshire, Buckinghamshire, Berkshire, Northamptonshire, Gloucestershire and Wiltshire. Homes were in larger towns such as Reading and Oxford as well as small towns, villages and remote rural locations. The homes included small flats and a range of houses such as urban council housing, farmhouses, housing estate properties and large country homes.

3.3.1.2 Sampling and recruitment approach

3.3.1.2.1 Background to decisions about sampling strategy and participant numbers

Qualitative research usually involves non-probability sampling, as statistical representativeness, prevalence or incidence are not sought (Ritchie et al., 2003). There is no

easy formula to guide researchers concerning participant numbers. From a practical viewpoint, Ritchie et al. (2003) suggest that as a rule of thumb, projects involving interviews should have less than fifty participants, as otherwise the data tends to become too hard to manage. Ritchie et al. further comment that there is a point of diminishing return, when increasing a sample size will not add anything new to the existing data. Time and financial constraints may also be factors in determining sample size.

Aside from practical considerations, the research questions, focus, design and intended sampling strategy influence decisions about the number of participants recruited. In a purposive sampling strategy, participants are recruited sequentially, using specific selection criteria, with the final sample meeting requirements for diversity and symbolic representation (Ritchie et al., 2003). A further point, as Richards (2005) suggests, is the amount of data that have been gained via the sample numbers needs to have sufficient scope to answer the main and supplementary research questions that arise. Therefore, if at a particular point the sample number enables achievement of these outcomes, then sufficient participants will have been recruited.

A type of purposive sampling known as theoretical sampling can also be used, although it was not used in this study. In theoretical sampling, new participants are recruited not sequentially but iteratively, with very specific, targeted recruitment driven by emerging issues or questions arising from the data analysis over a period of time. 'Saturation' of the data is deemed to have been reached when no new questions or issues arise from the data analysis. This is normally adopted in grounded theory designs, but tends to be somewhat more time consuming than other forms of purposive sampling (Ritchie et al., 2003); this was one reason why this sampling method was deemed to be impractical in this study, which had time limitations.

Another reason for not adopting theoretical sampling was the difficulty in recruiting sufficient numbers of participants. Using a sequential purposive sampling strategy (as described below) enabled all eligible participants to be invited. In the context of this study, theoretical sampling would have been difficult, as there was a limited number of available participants, and these were recruited through a slow and laborious process; it would not have been appropriate to have turned down willing participants who met inclusion criteria in order to target participants who could help answer very specific questions about theory. Despite this possible limitation, no new issues were identified during the analysis that could not be explored within the existing sample.

3.3.1.2.2 Sampling strategy and participant numbers

In this study design, a sequential, purposive sampling strategy was used for recruiting parents to the study. The criteria for selection were specified in advance, although these only related to the child's age (16 years or under) and disease diagnosis (asthma or diabetes). The intention was that the final sample would represent parents from a wide range of social backgrounds, different marital status, with their child having been diagnosed for different lengths of time, and be from different age groups. This degree of variability was achieved, as is shown in section 3.3.2. It had been estimated that a sample of parents of 30 children (which would include some fathers, so the sample size would be between 30 and 60), would enable sampling of the range of these factors and would also be a manageable number for data analysis; also, similar qualitative studies have recruited similar or fewer numbers of participants, suggesting this number to be probably sufficient.

All three specialist nurses who worked at the clinics attached to the main study site were recruited, and one support group leader to represent the perspective of a group. Interview data from these participants would be used to help inform any revisions to the semi-structured interview schedule.

3.3.2 Ethics

3.3.2.1 Summary of ethical considerations

The main ethical consideration related to the fact that parents of children with a chronic illness are a group that experience a significant amount of stress, and it would be important not to add to that as a result of interviewing them. Although interviews are not physically invasive, the process may stimulate participants to recall distressing events or thoughts and could evoke related emotions that might be disturbing for participants. Therefore, their psychological support needs were considered. Although potentially distressing for some parents, such interventions may be therapeutic because parents would have access to an empathetic listener who is only interested in their perspectives.

It is important that participants do not feel coerced to participate in research, so the recruitment procedure needed to ensure that sufficient time would be allowed for them to consider a decision about whether or not to take part in the study. The researcher's lack of

involvement in the child's care in any way was important in avoiding risk of parents feeling coerced to participate. Participants would need to be reassured that they could withdraw at any time, without having to provide an explanation. Risks of participants feeling coerced may also be reduced by not offering such incentives (such as financial ones) as may lead an individual to take part for this reason alone.

A sound research design conducted by researchers with adequate preparation is important for ethical research, as otherwise the potential risks of the study to participants would outweigh the benefits of the outcomes.

3.3.2.3 Ethical approval process

Description of the initial process

Following discussion of the research strategy with my supervisors and specialist paediatric nurses who cared for children with these chronic illnesses, an ethics application was made to COREC, which was approved on 21 May, 2004. Trust management approval was also gained. (See Appendix 3.1 and 3.2 for letters of approval). A university ethics application was completed but not required by the university. The initial application included a request for permission to undertake observations of health care interactions of parents in their home, whilst accompanying the nurse specialist on her visits. This was felt to be important for the original research objective, which included developing an observational instrument. Some amendments were made to the agreed ethical approval after commencement of the study, which were agreed on 19 August, 2005. (See Appendix 3.2 for COREC letter).

3.3.2.4 Gate-keeping and access issues (leading to need for amendments to some sample characteristics and recruitment process)

COREC had not required consultation with medical practitioners prior to submission of the proposal, as the participants were not patients. In the original proposal, it was planned that the main data collection method of interviews would be complemented by observational visits. However, following the successful ethical approval, the key medical practitioner for children with diabetes raised some concerns about carrying out observational visits, the recruitment of the most vulnerable parents, and psychological support available for parents.

Before this doctor would allow access to parents via the clinic, she required the following amendments to be made to the recruitment process:

- 1) No parents whose child was diagnosed less than one year ago, who had more than once child with diabetes or who had previously taken part in a research study may be invited to participate. In addition, any other parent that the team deemed unsuitable to be recruited may not be invited to take part.
- 2) As the facilities for psychological support via the diabetes team were limited (i.e. 6- month wait to see a psychologist), ready access to professional psychological support must be available immediately to parents, funded by research monies.
- 3) The interviewer must offer this psychological support at the end of the interview, and telephone each participant 3 days after each interview to ask if they would like this support.
- 4) Permission was not given for access to homes whilst accompanying the nurse on visits, as these parents had children who had been recently diagnosed, so were excluded by point 1 above.

These conditions were complied with, with potential funding being secured through some research money available within the School of Health and Social Care, where the researcher is employed.

The asthma medical practitioners were very supportive of the study design, and imposed no restrictions. However, they considered that there would possibly not be enough home visits being undertaken by the nurse to enable recruitment of a sufficient number of participants.

Only a proportion of the respiratory clinic attendees had asthma, with the rest having a different respiratory problem (including for example, cystic fibrosis or congenital lung problems). The nurse did not know all the asthma patients personally and would not recognise many of them by sight in order to approach them to give them the study information and letter. Therefore, in order to decide who to recruit, she looked through the case notes (which became available on the morning of the clinic) to identify potential participants. This was time consuming in a busy clinic, especially as she was the only asthma nurse in the clinic. It was challenging for the nurse, in a busy clinic, to not only identify who the potential participants were, but to remember to approach them before or after they were visiting the

doctor or physiotherapist. This resulted in hardly any letters being handed to potential participants and after 1 year, only 4 participants had been recruited.

Following discussion with the team, they encouraged the researcher to apply to COREC to seek an amendment to the recruitment process which was done, and the amendment to the recruitment process was agreed on 19 August, 2005. The procedural alterations were as follows:

- 1) The researcher would attend each clinic where children with asthma were booked to attend. If the researcher was present, they would be available to remind and support the nurse in the process of identifying appropriate participants, introducing them to the researcher and handing out letters. Personal contact between parents and researcher was felt to be helpful, as parents would have an opportunity to discuss the study in person at the time, potentially aiding recruitment.
- 2) To cause less impact at busy times, the nurse would check on the hospital computer records at least one week in advance of clinics, how many children with asthma were booked to attend each clinic. This avoided the nurse having to go through case notes on the morning of clinic, which meant that most suitable parents were approached during the clinic. This significantly improved recruitment, with nearly all participants being recruited within a few months.

A similar process was agreed with the diabetes clinic team, as recruitment had been a bit slow there as well. However, after two months of following this process, and with 4 parents still to recruit, the key medical practitioner of the diabetes team asked the researcher to stop recruiting. The reasons given were that the study recruitment had lasted one year, so this was long enough, and also two other research projects had commenced with children with diabetes; therefore, continued recruitment attempts to this study could discourage parents from agreeing for their child to be participants in the new studies. Fortunately, it was possible to recruit the remaining participants via a clinic at a different hospital that was part of the same hospital Trust (so did not require separate ethical approval).

3.3.2.5 *Change from original plan and explanation*

It should be noted that the method described above differed from the original plan for this study. The initial aim of this research was to develop measures of parent adjustment. It had been planned to interview participants, transcribe interviews, analyse the text, develop categories and code text using content analysis. It was then intended to extract statements from the interviews that could be used as questionnaire items to be piloted and validated as part of a new instrument. The plan changed as it was being found that the interview data were extremely rich and detailed, including more than would have been required for the development of measures. Much of these data would have needed to have been ignored had the original plan been followed; also, as the material evident in the interview data included issues not covered in published studies, it was decided to modify the aim. It is still intended to develop measures as an aim of a post-doctoral study.

3.3.3 **The Sample**

3.3.3.1 *Description of the sample groups and participants*

The background to the choice of parents with children from the two illness groups of asthma or Type 1 diabetes was explained. One or both parents of 32 children (and in one case, a grandmother) were recruited for the most part through hospital clinics for children with respiratory problems or diabetes. As mentioned in the previous section, two non-clinic parents heard about the study informally and volunteered to be interviewed. Although one parent in the asthma group had two children with asthma, the interview focused on the son with severe asthma; the presence in this family of an older daughter with mild asthma is however acknowledged in the headings of tables in the empirical chapter appendices in relation to participant A_12. Participant A_14 also had other children with asthma, although these were now adults and not living at home, so these were not acknowledged in the sample descriptions. A summary of the sample group characteristics is presented in Tables 3.3 and 3.4 below. The participant details are shown in full in Appendices 3.1 and 3.2.

The parents were white and all were British or European (except one from South America); 9 were single mothers. The participants represented all socio-economic groups and areas of domicile (rural and urban areas). One additional father and one mother, who had initially agreed to participate, withdrew from the study prior to the interview. Although they were not

asked to give a reason, the father (whose wife was interviewed) stated he was withdrawing due to his symptoms of depression, and the mother withdrew due to time constraints. The final sample included 32 mothers, 7 fathers and one grandmother of children with diabetes or asthma, three specialist paediatric nurses, one support group leader and multidisciplinary team members working in a paediatric respiratory or paediatric diabetes clinic.

Note: In Tables 3.3 and 3.4, social class categories are based on Runciman (1990) - see Table 3.5 overleaf for an explanation. According to this framework, participants are normally categorised according to the social class of the father, although clearly in some cases the mother's social class grouping could be higher. However in this sample, this was not the case as parent occupations were either from the same social class grouping, or the father's was higher. In the case of single mothers, the occupation of the mother determined the selected social class category.

Table 3.3: Asthma Group Characteristics

Social class based on Runciman's* 7 social classes by occupation n=16 family groups.	Marital status (figures include both partners if both participated) n=19 individual participants (within the 16 family groups)	Age and gender of child with chronic illness n=16 children with asthma	Time since diagnosis n=16 children with asthma	Numbers of siblings of affected child n=16 children with asthma
1 x SC 1 3 x SC 2 7 x SC 3 1 x SC 4 1 x SC 5 3 x SC 6 0 x SC 7	married or co-habiting = 13 single, divorced or widowed = 6	<i>age ranges:</i> 3 aged 2-4 years 6 aged 5-11 years 7 aged 12-16 years <i>gender:</i> 11 male 5 female	1 child diagnosed up to 2 years ago, 1 awaiting confirmed diagnosis 5 children: diagnosed 3-5 years ago 9 children: diagnosed 6 or more years ago	3 children: no siblings 4 children: 1 sibling or step-sibling 9 children: 2-4 siblings or step-siblings

Table 3.4: Diabetes Group Characteristics

Social class based on Runciman's* 7 social classes by occupation n=16 family groups.	Marital status (figures include both partners if both participated) n=22 individual participants (within the 15 family groups)	Age and gender of child with chronic illness n=16 children with diabetes	Time since diagnosis n=16 children with diabetes	Numbers of siblings of affected child n=16 children with diabetes
2 x SC 1 3 x SC 2 4 x SC 3 4 x SC 4 1 x SC 5 1 x SC 6 1 x SC 7	married or co-habiting = 19 single, divorced or widowed = 3	<i>age ranges:</i> 0 aged 2-4 years 7 aged 5-11 years 9 aged 12-16 years <i>gender:</i> 8 x male 8 x female	3 children diagnosed up to 2 years ago 8 children diagnosed 3-5 years ago 5 children diagnosed 6 or more years ago	1 child: no siblings 8 children: 1 sibling or step-sibling 7 children: 2-4 siblings or step-siblings

Table 3.5: Explanation of Social Class Categories by Runciman (1990)

Social class	Examples of occupations / statuses
1. Upper	Corporate owner, senior manager, people with exceptional marketability
2. Upper middle	Higher grade professional, middle manager
3. Middle middle	Lower professional, middle manager, medium-sized owner
4. Lower middle	Routine white-collar (clerical, etc.)
5. Skilled working	Electrician, plumber, skilled self-employed
6. Unskilled working	Shop assistant, check-out operator
7. Underclass	Unemployed, living solely on benefits

The children of the parents interviewed were aged from 2 - 16 years. All but one child were diagnosed between one and 14 years ago (with most asthmatics being diagnosed about age two). The asthmatic children from the clinic population were on several types of medication and had experienced at least one emergency hospital admission within the last year. The diabetic children were all insulin-dependent, so had the same requirements of a daily regime involving insulin injections, blood testing and diet monitoring. Few of these children had had many hospital admissions since diagnosis, with some having had none.

Other participants who were interviewed included a leader of a parent support group for children with diabetes (who also was a parent of a diabetic child), one asthma specialist nurse and two paediatric diabetes specialist nurses who worked in both hospital and the community.

The members of the multidisciplinary team that were observed included, for the diabetes group, two doctors, two specialist nurses, a dietician, a social worker and social work student. The asthma team observed included two doctors, one specialist nurse and a physiotherapist.

3.3.2 Instruments and Procedures

3.3.2.1 Background to selection of data collection methods and design of semi-structured interview schedules

In-depth interviewing was considered to be the most appropriate data collection tool for the research objectives. Such interviews make it possible to gain large amounts of data quickly and enable the researcher to explore meanings held by individual participants (Marshall and Rossman, 1999). Compared to other qualitative data collection methods such as focus groups, observation or document reviews, in-depth interviewing is more likely to achieve these objectives, although is probably more time-consuming than some of these other methods.

Marshall and Rossman (1999) explain that in-depth interviews are much more like conversations than formal question-answer sessions. As such, a semi-structured interview schedule is mainly a guide to issues to explore during interviews, since the interview is jointly constructed by researcher and participant. Participants might express very pertinent points relevant to the research objectives that are not specifically mentioned in questions on a semi-structured interview schedule, but instead are triggered by them. Nevertheless, a semi-structured interview schedule is useful in helping to focus the issues for exploration. In

research areas where some evidence already exists, it is important that the topic areas discussed at interview consider this. In this study, available literature and other research studies informed the scope and range of questions included in the interview schedule.

3.3.2.2 *Semi-structured interview schedules and field notes*

Semi-structured interview schedules were developed for parent, specialist nurse and support group leader participants, initially based on a review of literature. There were two parent interview schedules (one for each illness group), although the copy in Appendix 3.9 shows only one (incorporating the names of both illnesses). A similar interview schedule was developed for specialist nurses and the support group leader (as shown in Appendix 3.10).

The interview schedule for the nurses and support group leader provided a guide for the first interviews of the study. Findings from these interviews, as well as from multidisciplinary team observations, informed minor adjustments to the parent interview schedule. This resulted in inclusion of additional prompts in the areas of responses to clinic attendance, the degree of parental treatment monitoring, managing holidays, transitions from primary to secondary schools and transitions across age groups.

Field notes were used to record observations during and after multidisciplinary team meetings. In addition, field notes were used to record any observations, impressions and questions following data collection from nurse, support group leader and parent interviews. Notes on observations and impressions served as a reminder of contextual or other factors that could help to further understand the behaviour or responses of participants, or to document ideas or questions that could shed new insights relating to the research objectives.

A summary of the key themes contained within the interview schedules is presented below:

- Parent or guardian's experiences and feelings about the illness:
 - At the time of diagnosis, currently, and when considering the future
 - During subsequent acute episodes of illness
 - Perception of how the illness has affected their child's life and relationships, e.g. with the parent, at school and with friends, and how their child's responses have changed with age
 - How the child's illness generally has affected parent's life and functioning (e.g. managing holidays)

- Family interactions:
 - Family members involved in illness management, and their levels of responsibility / functioning
 - Impact of illness on family relationships and functioning, including with siblings
 - Positive and negative times in family relationships

- Interactions with school personnel
 - Staff knowledge and support
 - Changes between primary and secondary school,
 - When managing school trips, outings, sports
 - Positive and negative times in relating with school personnel

- Medical treatment – home environment
 - Child’s treatment / medication regimes (preventive / daily management), and any side effects
 - Child’s understanding of treatment / medication regimes
 - Experiences with health professionals in managing treatment at home
 - Symptoms when acutely ill and how they are managed, and by whom
 - Positive and negative times in managing treatment at home

- Medical treatment – hospital or surgery environment
 - Frequency of attendance at clinics / any acute admissions to hospital, and child / parent feelings and responses
 - Parent supportive actions during such experiences
 - Experiences with health professionals during clinic visits or acute admissions
 - Positive and negative times in hospital or surgery attendances

The topics selected for the interview schedules drew upon areas identified in the literature that are thought to be important for chronically ill children. Therefore, parents’ perspectives on their children’s experiences in daily life, with peers, at school, in family life and in health care settings were incorporated into the interview schedule. It had been noted that these areas were also assessed within a measure of children’s quality of life, PedsQL developed by Varni et al. (2001); this is used to assess chronically ill children’s physical, emotional, social and school functioning. Whilst quality of life is not the same as adjustment, the former may be considered a reflection of the latter. Not all aspects of child adjustment that would need to be included in a similar parent interview schedule are evident in the PedsQL. Firstly, this

instrument focuses on identifying problems rather than recognising the features of optimal functioning, which is of interest in this study. Also, the PedsQL is an individual child measure and does not aim to assess, for example, family dynamics in the context of child adjustment.

There is some literature showing that spousal, sibling and other dyadic perspectives need to be considered when assessing parental adjustment. For example, Derouin and Jessee (1996) found that some siblings reported strengthened family relationships and greater personal independence as an outcome of their brother's or sister's illness, but they also experienced more worry about their ill sibling, and reported feelings of jealousy of the attention paid to the ill child and resentment at restrictions of family events. It seems likely that such sibling responses and their adjustment to being in a family with an ill brother or sister could be relevant to parental adjustment. Similarly, Williams et al. (2002) found that children's knowledge and attitude towards their sibling's illness and feelings of social support were related to family cohesion and the well sibling's behaviour. These examples show that attention needs to be paid in a parent interview schedule to the experiences and dynamic relationships within and outside the family.

3.3.2.3 *The researcher as an instrument*

It has been expressed by some authors (Lincoln and Guba, 1985; Marshall and Rossman, 1999) that in qualitative studies, the researcher is the instrument since their interactions with participants are fundamental to qualitative research paradigms such as constructivism. The interview represents the context within the researcher is able to enter into the lives of interviewees, and this requires consideration of a number of issues.

Among the strategic issues are decisions about deploying the self (Marshall and Rossman, 1999). These authors suggest that researchers need to decide about their degree of *participantness*; these decisions relate to how much of the self is revealed to participants and allowed to be part of the data. The participants in this study knew that the researcher was a nurse by background; it was acknowledged that revealing this aspect of the self could influence the nature or depth of participant responses in areas such as relationships with health professionals or the child's responses to treatment. It is likely that the researcher's professional background and participants' awareness of this influenced the data, including the details of topic areas explored and the interpretations of the meanings within communications. It is important to be explicit about these influences when analysing and discussing results.

Intensiveness and *extensiveness* are other aspects of self-deployment mentioned by Marshall and Rossman (1999) that will influence the process of data collection and analysis. *Intensiveness* refers to how much time is spent with participants over a period of time, whilst *extensiveness* refers to the depth of exploration of topics in interactions with participants. A researcher who can interact with participants over a long period of time may be more able to build up a trusting relationship and possibly as a result be more able to access true experiences, beliefs, feelings and attitudes of participants. However, this is time consuming and might be unnecessary for the research objectives; also, the need for multiple interviews could be a deterrent for participation. One long interview on one occasion (as in this study) may be equally successful in accessing rich, valid data if the interviewer has skills of engendering trust and being both proactive and responsive (Lincoln and Guba, 1985). A researcher in this situation needs to be responsive, respectful, honest and adaptable, and able to recognise and respond to overt and subtle cues. In fact, the success of in-depth interviews depends to a large extent on the personal and professional qualities of the individual interviewer (Legard et al. (2003).

Legard et al. (2003) note that many authors make reference to the need for interviewers to have certain qualities including:

- an interest in, empathy and respect for people as individuals
- an ability to establish good rapport with people from all walks of life, putting people at ease and creating a climate of trust
- an ability to listen in order to digest information, understand, and probe interviewees, remaining totally focused on the interview
- a clear, logical mind, concentration and stamina, enabling the interviewer to think quickly in the interview context, following up issues that arise
- a good memory and ability to be adaptable, in order to help the interview to be mutually constructed and coherent
- a sense of curiosity, to stimulate deeper exploration

This mixture of personal qualities or abilities was recognised as being needed when selecting interviewing as a data collection method. These are the same qualities and abilities required for effective interviewing of individuals in a health care context, an area where the researcher has significant experience as a nurse. This experience has involved developing skills of encouraging deeper-level responses from individuals such as parents of ill children, including

as open questioning, appropriate body language, recasting interviewee responses to seek confirmation of meaning, and showing empathy through reflecting interviewees' expressions. Although previous interview experience has been in a therapeutic context, in a research context there is a similar objective of encouraging interviewees to express their beliefs, thoughts and feelings, sometimes of a sensitive nature, albeit with different motives. It was therefore considered that specific interview training was not required prior to commencement of data collection.

3.3.2.4 *Individual and Joint Interviews (planned and unplanned)*

Most of the interviews were with individual parents, although in seven instances (22% of interviews), the father and mother and in one instance, the mother and grandmother were interviewed together, as had been planned and agreed. Arksey (1996) refers to these types of interviews as joint interviews, defining them as when one researcher interviews two people together, for the purpose of obtaining information about how the pair perceives the same events or phenomena. She notes that that these are qualitatively different from individual interviews in that single interviews are individual reconstructions of events, opinions and so forth, whereas joint interviews involve accessing shared or jointly constructed meanings. Morris (2001), who carried out joint interviews with patients with cancer and their carers, expressed other unique features of joint interviews:

What makes joint interviewing different from individual interviewing is the interaction between participants, who usually have a preexisting relationship....Joint interviewing provides the opportunity for combining something of the intimacy of an individual interview with the public performance of a focus group. In particular, it places emphasis on the relational possibilities of a pair's situation, asking them to represent themselves not just as individuals but also as concurrent participants in a relationship; mutually created meaning is highlighted as they speak'. (p. 558)

Prior to conducting interviews, the strategy for interviewing two parents had been considered, i.e. to interview the parents (or mother and grandmother) separately or jointly. Arksey (1996) and Morris (2001) argue that there are advantages and disadvantages of each of these options, which are expressed in the following table:

Table 3.6: Advantages and Disadvantages of Joint and Individual Interviewing

Advantages of Joint Interviewing over Individual Interviewing	Disadvantages of Joint Interviewing over Individual Interviewing
1. The outcome is likely to be a better understanding of the experience as shared events or phenomena (Morris, 2001).	1. One interviewee might be dominant, restricting the opportunity to hear the voice of the other interviewee (Arksey, 1996)
2. Joint interviews are likely to be more time-efficient, especially as the accounts are often similar (Morris, 2001).	2. Shared perspectives that are presented may reflect a publicly rehearsed account, possibly being less true than private accounts, (Cornwell, 1984, in Morris, 2001)
3. Separate roles or degrees of engagement in situations or events may be more readily revealed through interviewee interactions during interviews (Morris, 2001). For example, if a mother is the main carer responsible for illness management, the father may show more deference regarding this during the interview.	3. Joint interviews may be harder for the interviewer to control, as there is usually dialogue between interviewees, leaving the interviewer as an observer (Arksey, 1996).
4. Joint interviews may be preferred by dyads rather than individual interviews as they acknowledge beliefs that there are no 'secrets' between the individuals; by the researcher asking to do separate interviews, it gives the impression that they believe secrets exist (Morris, 2001).	4. Joint interviews are often longer so requiring greater interviewer and participant concentration and stamina; there is a risk of loss of focus (Arksey, 1996).
5. Joint interviews may be less intrusive than individual ones, as one person does not need to stay out of the way in their own home whilst the other is interviewed in private (Morris, 2001).	5. Couples have a concern about maintaining the stability of their relationship, so may avoid discussing emotionally loaded issues in a joint interview (Benjamin, 1998 in Morris, 2001)
6. One interviewee may fill in 'gaps' left unsaid or forgotten by a second interviewee, be able to contribute to fuller accounts or trigger new thoughts or constructions (Morris, 2001).	6. There is an ethical concern that joint interviews may increase risks of confrontation between interviewees (Pahl, 1989 in Arksey, 1996).

In addition to the above issues, a further consideration in deciding whether to undertake joint interviews was participant choice. By providing participants with the option of either joint or individual interviews, it emphasises the equality of the relationship with the interviewer, and empowers the participants through providing choice (Morris, 2001). When couples were asked if they wanted to be interviewed together or separately, they all chose to be interviewed

together. It will be important in the data analysis phase, to consider where possible whether some of the disadvantages listed in the table above have impinged on the results. Points 1-5 listed under disadvantages may have some import; however, point 6 was not generally observed, although evident to some extent in one of the joint interviews.

Whilst these seven interviews were deliberately planned as joint interviews, there were some instances of ‘gatecrashing’, particularly by children and in one instance by a husband (whose wife had not extended the research invitation to him and told him to go away when he started speaking during the interview!). Older children in particular whose parents had agreed to participate in the study often showed an interest in the study themselves, as after all, the parents were being asked to participate because of them (if they were the child with the chronic illness). If these children asked the interviewer if they could participate, it was sensitively explained to them that the study was about parents and that another study going on at that time was finding out about how children felt.

However, some children (child with chronic illness and/or siblings) did enter the interview situation for part of the time and in one instance the whole time (whether at home or with their parent at clinic). Sometimes they just listened, whilst at other times they independently made contributions or were encouraged to do so by their parent. This was particularly the case when discussing the child’s personal experience (e.g. at school, with peers or during hospital visits). It seemed appropriate that when such experiences were being discussed, that the interviewer should engage in eye contact and express other inclusive non-verbal signals with both child and parent during this time, thus acknowledging the child’s contribution whilst not directly requiring it.

In no cases did parents ask the children to leave, which did pose an ethical dilemma as no consent from an ethics committee had been sought to include children in the interviews. It did not feel appropriate for the interviewer to ask the children to leave, particularly as this ‘intrusion’ usually happened in the family home, where the interviewer was a guest. The opinion of an ethics committee chair was subsequently sought on this matter, who suggested that if it seemed appropriate to include data from children (or the one instance of a husband), then the parents (or husband) would be contacted to ask if the anonymous information could be included in the presentation of results.

3.3.2.5 *Methodological issues arising from interviews*

The presence of children

The point raised above about children being present at interviews is relevant from a methodological as well as ethical perspective. On one occasion, where the child was present throughout the interview, the impression was given that the parent felt restricted in what she could say in front of her child, particularly when it came to discussing her own feelings about changes in the family lifestyle or her working life as a result of the child's illness. In other interviews where a child or children were present, they wandered in for short periods and then left, so parents were able to expand on points in their child's absence. There is little doubt that in this one interview, less depth was achieved than might otherwise have been the case.

The interview process

Although all of the topic areas on the interview schedule were explored with the parents, the participant responses did not always follow these questions. Sometimes parents volunteered information before being asked the related question, and at other times they answered a different question from that posed at the time, although the responses were still relevant to the study objectives. Many parents wanted to tell their 'story' and would speak for long periods of time about their experiences, thoughts and feelings, without interruption. These were among the longer interviews, some lasting over two hours. For some parents, this ability to 'tell their story' was therapeutic, as they said this to the interviewer at a later point. This 'story telling' was particularly evident in joint interviews, where parents would converse with each other about their thoughts, feelings, perceptions and versions of events. This required some degree of interviewer skill to ensure that the topic areas were considered and to maintain focus. Nevertheless, it demonstrated that parents felt at ease during the interviews, potentially contributing to a context in which rich and true meanings could be revealed.

Inevitably, some parents, when discussing emotionally charged issues or traumatic events showed some distress, for example upset expressions with tears, or changes in voice tone indicating emotional tension. No parent became distressed more than momentarily, or became so distressed that they were weeping. Had this occurred, the participant would have been asked if they wanted to continue with the interview. On the occasions when parents did show some momentary upset, the interviewer showed empathy and acceptance, acknowledging the parents' feelings. As requested by the senior diabetes consultant, the parents of diabetic children were contacted several days post-interview to offer referral for

counseling support. All but one participant couple declined; the couple who accepted had intended to seek counseling support in any case and their acceptance of this offer was unrelated to the interview.

3.3.2.6 Recording equipment and computer software

To minimise interviewee reactivity, it was felt important to select interview recording equipment that was as unobtrusive as possible, so a digital voice recorder was used. This does not require an external microphone to be placed near those speaking, and its size is unobtrusive. Furthermore, the interview can be downloaded as a voice file directly to a computer, increasing data security and making transcription easier. These factors influenced the decision to use a digital recorder for all but the first two interviews (when a conventional tape recorder was used because a digital recorder was not available).

The voice recorder used was Olympus DSS Player 2002, with associated computer software (version 1.4.0), with an Olympus AS-2000 PC transcription kit (incorporating foot pedal, headset and software). The voice recorder had an inbuilt microphone (although an external one was available), suitable for recording small group interviews. The interviews were recorded as voice files that could be downloaded as digital sound files onto a computer, and then listened to via headsets whilst transcribing interviews into Word.

It was decided to use NVivo 7 software for the data analysis, as a qualitative data analysis package provides considerable scope for data exploration (Richards, 2005) and this was the package adopted within the Psychology Department at Oxford Brookes University; access to facilities and support would therefore be more available than with other packages.

3.3.3 Data Analysis

3.3.3.1 Overview of data analysis method

Thematic analysis was the method chosen for the data analysis. This method is used for identifying, analysing and reporting themes or patterns within qualitative data. According to Braun and Clarke (2006), it is widely used although poorly demarcated, possibly because it is not associated with specific theoretical perspectives or prescriptive data analysis guides. In fact, it may be seen more as a tool for use across different methods (Boyatzis, 1998, cited in Braun and Clarke 2006). Grounded theory in this study provides guiding principles for the

data analysis, particularly in relation to the development of theory through interpretive data analysis.

3.3.3.2 Rationale for data analysis method

Thematic analysis differs from more conventional grounded theory procedures, where data collection and analysis is an iterative process. As mentioned previously, through constant comparison of new data with previous data, posing questions and exploring relationships, the researcher specifically targets the type of participants needed to explore these questions further. However, as pointed out in section 3.3.1.2.1, the fact that theoretical sampling was not undertaken meant that conventional grounded theory data analysis procedures were not feasible. Another aspect of conventional grounded theory procedures is the initial coding of text on a line-by-line basis. This procedure requires a considerable investment of time for data analysis, which is not an expectation in other qualitative data analysis approaches, such as thematic analysis. These considerations led to the decision to use thematic analysis as a data analytic method.

Braun and Clarke (2006) suggest that thematic analysis enables development of core skills relevant to a range of qualitative methods, particularly in relation to ‘thematising meaning’. It can be used to summarise key features of a large corpus of data and / or enable ‘thick description’ of data sets. It is flexible in the sense that it does not require adherence to particular theoretical or procedural criteria. Also, its use is compatible with a range of paradigms, including constructivism. Braun and Clarke (2006) also argue that has the potential to generate unanticipated insights that may be useful for practical purposes, including informing policy development. These were all points in favour of selecting this method of data analysis for this study.

However, some of the strengths outlined above might also be seen as weaknesses, which also needed considering in the decision about choosing this method. For example, Braun and Clarke (2006) point out that not having a particular theoretical or paradigmatic orientation means that it is not ‘branded’ in the way that are other qualitative methods such as discourse analysis or interpretive phenomenological analysis, nor are there rigid procedures that must be followed. This may mean that its other researchers are more sceptical about whether the research has been undertaken in a systematic manner, with proper attention to quality and robustness. In the absence of prescribed procedural criteria, it is important that procedures that are followed at every stage of the research process are reported, to ensure transparency.

It is also important that researchers are explicit about their theoretical framework, as there is no interpretive power in thematic analysis beyond description (Braun and Clarke, 2006).

It is considered that the weaknesses outlined by these authors have been taken into account in this study. As discussed earlier in this chapter, the paradigm that provides the focus of this study has been explored and clearly described, and a clear set of objectives have been identified that have the potential to generate theory. Finally, the account of procedures followed (section 3.3.4.4.) demonstrates that the data were analysed in a systematic and transparent way.

3.3.3.3 *Data analysis procedures*

Braun and Clarke (2006) outline six phases of analysing and reporting on data using thematic analysis, and this was considered to be a helpful framework. The phases are:

Phase One: Become familiar with the data and observe for patterns of meaning (themes);

Phase Two: Generate initial codes;

Phase Three: Search for themes;

Phase Four: Review themes;

Phase Five: Define and name themes;

Phase Six: Produce the report.

This approach was considered suitable for the intended research objectives and paradigm, and for research that is inductive and data-driven. To achieve the research objectives, it would be necessary to identify themes and develop codes rather than use a pre-existing coding scheme. Throughout these six phases, data interpretations, proposed coding, analytical processes and data recording processes were discussed and verified with the researchers' supervisors. These discussions ensured that rigour and credibility were maintained throughout.

This approach was used for analysis of both interview data and observational field notes recorded following the multidisciplinary team meetings.

3.3.3.3.1 *The phases of data analysis*

Phase One: Become familiar with the data and observe for patterns of meaning (themes)

Interviews were read through on numerous occasions and notes were made of key areas that parents talked about. These original themes were semantic (descriptive). A strategy was adopted where some whole interviews were read through and coded – i.e. a 'many-to-one'

strategy. This helped the researcher gain an overall sense of the issues that parents were raising, without getting weighed down with unmanageable detail.

Phase Two: Generate initial codes

The initial codes listed below were identified, forming ‘free nodes’ in NVivo:

Table 3.7: Initial Free Nodes

<ol style="list-style-type: none">1) experiences and feelings at diagnosis2) personal history with disease3) impact on parents' or family life4) feelings and adjustments over time5) feelings about the future6) feelings about parenting role7) feelings about family relationships8) feelings about emergencies or crises9) feelings about health or social services10) feelings about social support11) relationships with school12) beliefs about what helps13) symptoms of disease or treatment14) treatment or precautions15) child individuality and responses16) effects on child's life17) openness about the disease18) parent view of child feeling normal19) parent view of child friendships20) responses of siblings
--

During the initial coding process, it became evident that in passages of text where one of the following codes was used, they were also coded using the first two of the following ‘free nodes’. These were:

Free node 16: effects on child’s life (specifically their social life)

Free node 18: parent view of child feeling normal (which also related to the child’s social life).

Free node 19: parent view of child friendships (which related to the child’s relationships with friends and at school)

The first two nodes were similar (so were merged), as they encompassed parent responses concerning activities in the child’s social life, whereas the third was kept separate as it was more related to the nature of the child’s social relationships.

Phase Three: Search for themes

Subsequently, a ‘one-to-many’ interview coding strategy (one code at a time applied throughout all interviews) was adopted, and the codes were then grouped into 7 themes:

Table 3.8: Themes Identified in Phase 3

- Experiences and feelings over time (subsuming free nodes 1-2; 4-5 above)
- Family dynamics (subsuming free nodes 6-7 and 20 above)
- Personal and family life, work and recreation (free node 3 above)
- Relationships with wider social context (subsuming free nodes 9 and 11)
- Illness, treatment and precautions (subsuming free nodes 8, 13, 14 and 15*)
- Child’s response to illness (subsuming free nodes 15*, 17, and merged 16 and 18, 19)
- Coping strategies (subsuming free nodes 10 and 12)

*Free node 15 crossed these two themes

Phase Four: Review themes

A key theme that began to emerge early from the analysis (where all interviews were coded) was *illness, treatment and precautions*; a number of codes relating to this theme were developed in an iterative fashion. It was noted that some of the parent responses were general, but many were in the form of giving accounts of episodes that were atypical or typical for the parent and child. Some of these passages had a strong emotional component, whilst others illustrated parents’ beliefs and knowledge. It was considered that these distinctions were important for understanding parental adjustment, as different parents’ initial and subsequent responses to these episodes varied greatly, even when superficially the experiences seemed to be similar.

One factor that seemed to be important was the degree of predictability of the child’s illness episodes. Parents of children who had more unpredictable episodes appeared to experience more stress, possibly related to less feelings of personal control. This is not something that has been identified specifically by the small number of other researchers who have considered

child disease influences on parent adjustment. These mainly refer to effects of disease duration or severity (which isn't necessarily the same thing). For example, Holden et al. (1996) investigated factors affecting child and family adjustment to a child's chronic illness, which included disease-specific factors. These were disease duration, number of emergency room visits or hospitalisations and parent ratings of child disease severity.

Another theme where analysis was completed at an early stage was *effects on family life*. This included a code about *parents' feelings about their parenting role*. Coding material using the latter category also initially resulted in a substantial amount of material. Further refinements were made to this category and explicit inclusion and exclusion criteria were developed. An interesting observation was that parents' attribution of their child's behaviour varied, for example with regard to their beliefs about the child's behaviour being the result of the illness or drug side effects. Parent's responses to this behaviour (e.g. regarding discipline) seemed to vary with these attributions. Also, parents' sense of control (e.g. about responding to non-compliant behaviour of their child regarding treatment) seemed to be related to these attributions. It was considered that there could be interesting theoretical implications from the above observations. For example, Dix et al. (1989) highlighted that mothers' views on appropriate discipline relate very much to attributions – if a child is thought to be responsible for their own actions or not.

Phase Five: Define and name themes

An example of where this was initiated at an early stage was in relation to the theme about parent's feelings about their parenting role. Exclusion and inclusion criteria were developed, which helped to clarify the concept. (See Table 3.9 below):

Table 3.9: Exclusion and Inclusion Criteria Relating to the Theme of Parent’s Feelings about their Parenting Role

PARENTS’ FEELINGS ABOUT THEIR PARENTING ROLE – WHAT WAS CODED	PARENTS’ FEELINGS ABOUT THEIR PARENTING ROLE – WHAT WASN’T CODED
<ul style="list-style-type: none"> • Burden of responsibility; trusting or not trusting others to care for child • Child behavioural issue involving parenting response <ul style="list-style-type: none"> • child issues include ‘manipulative’ behaviour, non-compliance, eating or sleeping problems • Uncertainty of attribution of child behaviour issue: child development or treatment / disease-related? – Impact on parenting response • Parenting responses in everyday context, not necessarily attached to specific child behaviour (excluding physical management of illness): <ul style="list-style-type: none"> • ‘treating as special’ (e.g. over-protecting, empathising, compensating, rewarding) • ‘treating as normal’ (e.g. allowing independence, encouraging openness, ‘typical’ disciplining or boundary setting) • Feelings about impact on siblings, parenting responses 	<ul style="list-style-type: none"> • Guilt at not recognising early symptoms and protecting their child from harm (or pride in opposite) • Feelings about the child, e.g. sympathy, sadness, fear of death, pride, but no reference to parent or child behaviour • Feelings of being ‘inadequate’ or ‘successful’ in controlling disease (protecting from harm) • Feelings about impact on child, parenting responses (if exclusively about physical disease management, not relating to child behaviour) • Sibling responses (excluding parenting responses)

Some themes were modified or extended on the basis of the data analysis, For example, ‘Illness treatment and precautions’, ‘Physical responses and triggers’ or ‘Managing treatment’. Another original code, ‘Responses to emergencies’ was removed as this sub-theme was reconceptualised as part of one or other of the sub-themes concerning ‘episodes’.

Treatment compliance had originally been identified as a theme; however, this theme was removed in the first phase of identifying ‘free nodes’, as it was felt on reading the interview data further, to be too restrictive. It seemed that it did not capture the complexity of treatment management and reasons for success or failure, including the interactive (parent-child) components of this process such as child cooperativeness, and the lack of emphasis on whether not carrying out treatment was deliberate, in error or just due to forgetfulness. Also, as indicated in the previous section, some children and families, despite reporting very good compliance, nevertheless had poor illness control for various reasons. Therefore, it was felt

to be important to closely analyse parents' perceptions of treatment management and what they thought was going on during this process.

Phase Six: Produce the report

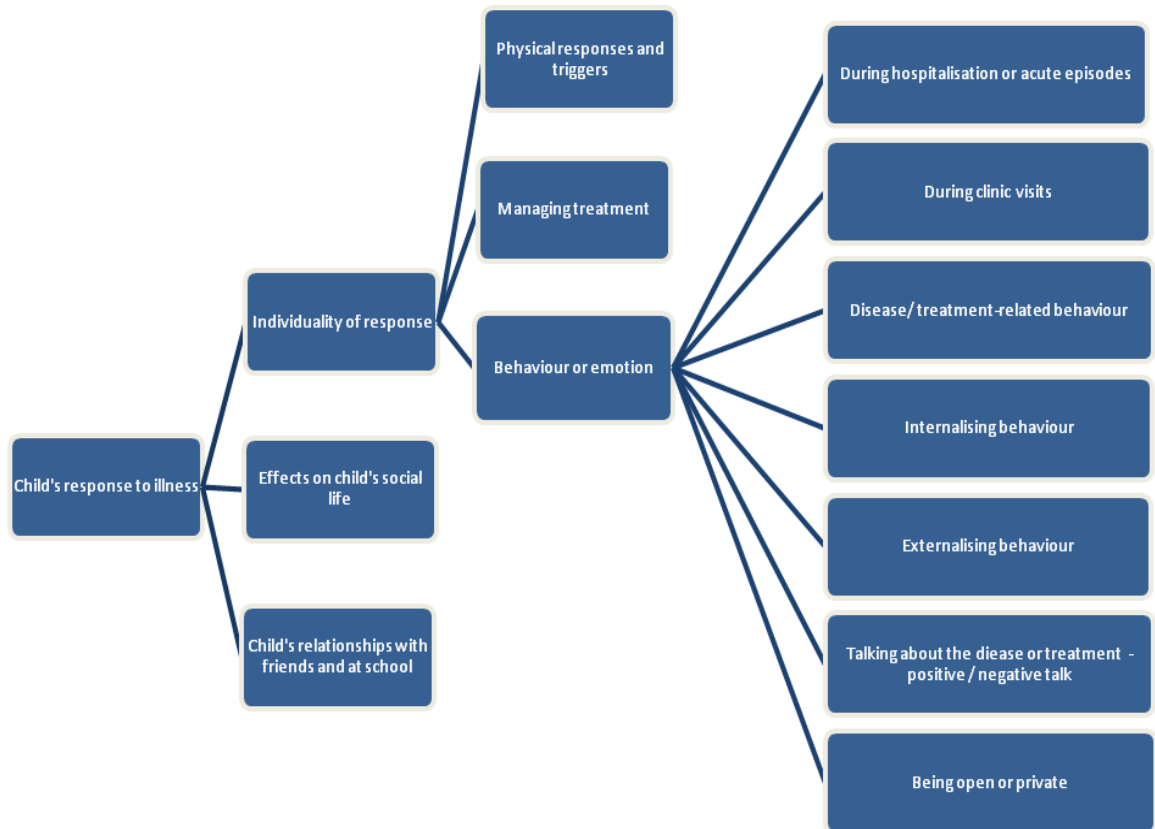
The empirical chapters of this thesis and associated appendices (Chapters 4-7) show how the data were explored and analysed, drawing upon grounded theory principles such as constant comparison. Prior to writing the empirical chapters (each of which was centred on specific research objectives) all relevant themes were identified that were connected with specific research objectives. The interview extracts associated with each of the themes for each chapter were then re-read. Similarities and differences in participants' responses were noted, using annotations on the printed extracts. Data from the themes were then indexed in tables (as shown in the appendices to Chapters 4-7). Such processes led to clarity, new insights and understanding of the nature of parents' adjustment and influences on the related experiences, as linked to the study objectives. The empirical chapter findings were brought together in Chapter 8, where the process and outcome of the development of new theory was presented.

3.4 THE STRUCTURE OF THE THESIS

3.4.1 General structure

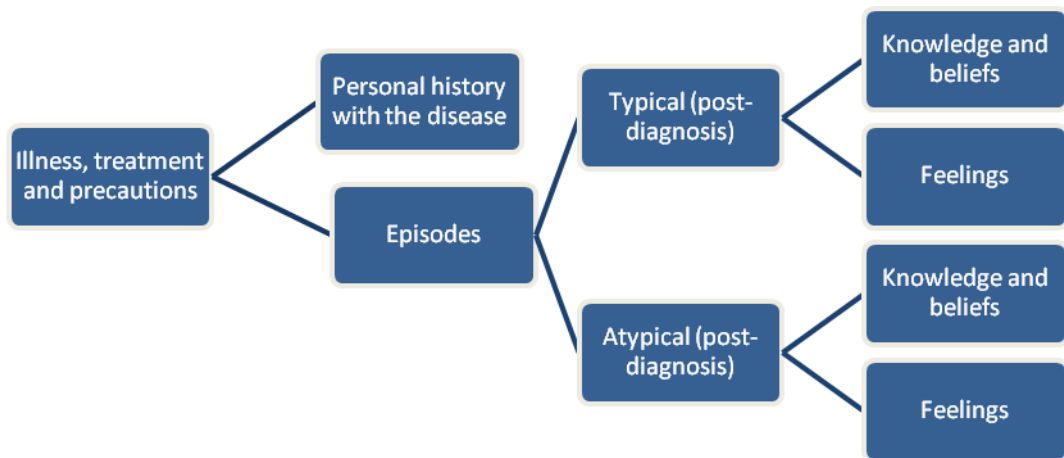
Chapters 1 and 2 have introduced and provided the background and justification for this study. The present Chapter has outlined the key study objectives, which have been considered within four empirical chapters (Chapters 4-7). The themes and sub-themes that arose from the data analysis are represented within diagrams in each of these chapters. The theme 'Child's response to illness' (as indicated on the left of the diagram shown immediately below) being discussed in Chapters 4 and 5. In Chapter 4, all of these themes and sub-themes will be discussed, except for two of the sub-themes of 'Individuality of response' to be discussed in Chapter 5 - 'Physical responses and triggers', and 'Managing treatment.

Diagram relating to the theme, 'Child's response to illness':



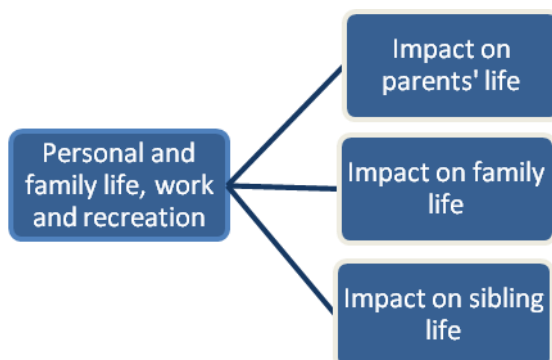
Chapter 6 focuses on the next theme of 'Illness, treatment and precautions' and its related sub-themes, as represented in the diagram immediately below. It shows that sub-themes relating to the parents' accounts of personal or family history, and illness episodes are discussed in this Chapter as well.

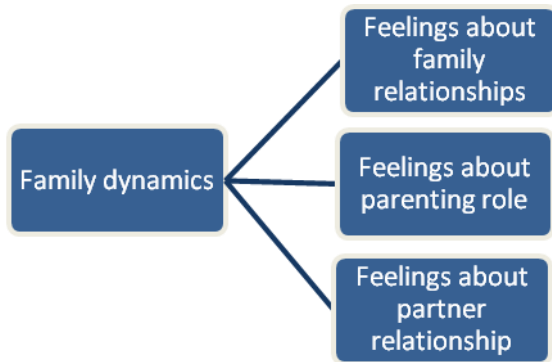
Diagram relating to the theme, 'Illness, treatment and precautions':



In Chapter 7, the findings that relate to the two remaining themes of 'Personal and family life, work and recreation' and 'Family dynamics' will be discussed, together with the related sub-themes.

Diagrams relating to the themes, 'Personal and family life, work and recreation' and 'Family dynamics':





Mapping of themes against study objectives and chapters

The following table shows how the study objectives and related themes were focused upon in specific chapters. Although Objectives 1 – 4 are addressed primarily in the four empirical Chapters 4-7, they are revisited in Chapter 8. Similarly, Chapter 8 incorporates findings related to those objectives addressed in the Chapters 4-7.

Table 3.10: Relationships between study objectives, themes and chapters

Study Objective Number and its Main Focus	Related Themes	Chapter Number and Title
<i>Objective 1:</i> Examine similarities and differences in parents' perceptions of the impact of the illness on the child's emotional and social life; consider how these perceptions influence parents' practical and emotional responses.	Child's response to illness (in relation to all subthemes except those in Chapter 5)	<i>Chapter 4:</i> Parents' experience of their child's social and emotional responses to a chronic illness
<i>Objective 2:</i> Examine similarities and differences in illness and treatment features and the illness management experiences of child and parent; consider the significance of these for the child's and parent's adjustment.	Child's response to illness (in relation to physical responses and triggers, and managing treatment)	<i>Chapter 5:</i> Parent perceptions of the child's physical responses and treatment management
Objective 2 is revisited. <i>Objective 3:</i> Examine the parents' experience of the effects of the child's illness and its management over time, as the years since diagnosis increase and as their child develops and matures.	Illness, treatment and precautions	<i>Chapter 6:</i> Parents experiences of illness episodes, variations and trajectories.

Study Objective Number and its Main Focus	Related Themes	Chapter Number and Title
Objective 4: Describe and examine parents' experiences since their child's diagnosis, in relation to their personal and family life, employment and leisure.	Personal and family life, work and recreation Family dynamics	<i>Chapter 7: Effect of the illness on parent and family life</i>
Objective 5: Ask questions about the data to explain similarities and differences in parental coping and adjustment, and how and why this changes.	All themes	Chapters 4-7 Chapter 8: Discussion and summary of proposed theoretical model
<i>Objective 6:</i> Discuss the findings and theoretical model, and the implications for future clinical practice and theory development.	As above	As above
<i>Objective 7:</i> Examine the psychological concept of adjustment and discuss its meaning in relation to parents of children with Type 1 diabetes and asthma.	As above	As above
<i>Objective 8:</i> Identify which parent behaviours may be reflective of better or less good adjustment, and any predictors of adjustment.	As above	As above

3.4.2 Reporting Conventions

The reporting of the findings will use particular conventions in relation to identification of respondents, representation of themes and sub-themes, sequence and structure of presenting and discussing results in Chapters 4-7, and the use of schematic diagrams and related symbols to represent syntheses of study findings within Chapters 4-7.

3.4.2.1 Identification of respondents

Respondent codes that start with A_ mean that one or more parents of an asthmatic child were interviewed in a single interview. Most of these interviews were with the mother alone, but others additionally included the father, grandmother or occasionally children. In the discussion, in cases where there was one participant (a mother), the term 'parent of A_' (or A_) will be used to describe the response. Where both mother and father (and in one case, a grandmother) were interviewed, the term 'parents of A_' or 'couple' will be used. The

exception to this will be where more than one participant was interviewed and there was a reason to distinguish between respondents (for example, the mother and father, or mother and grandmother have different perspectives). In this case, the terms ‘mother of A_’, ‘father of A_’ or ‘grandmother of A_’ will be used. The term ‘respondent A_’ or ‘A_’ may be used after the respondent has been identified as a parent, mother, father or grandmother. Similarly, respondent codes that begin with D_ indicate that the respondent’s child is diabetic, and other variations are as for the asthma group.

The number following A_ or D_ indicates the order in which the respondents were interviewed within the sample. In the interview extracts, M refers to mother, F to father, G to grandmother, C to child (who has the illness) and I to interviewer. The letter N was used in two extracts from nurse interviews. In a few cases, siblings contributed to interviews (with the parents’ encouragement). In these cases, the word ‘sibling’ is used in the interview text.

The column to the left of interview extracts will identify the respondent number and any key points. The child’s age group will be identified where this is relevant from a developmental perspective. Children’s ages were grouped as ‘pre-schooler’ (aged 2-4), ‘school aged’ (aged 6-11) and ‘adolescent’ (aged 12-16).

3.4.2.2 Representation of themes and sub-themes – theme diagrams

Theme diagrams, such as those found in Section 3.4.1 and excerpts from the theme diagrams will be used periodically, as reminders of the themes and sub-themes being discussed. The major themes are placed on the left of the diagrams, and sub-themes related to them are presented to the right. Where a particular sub-theme is being discussed, this will be highlighted in red, to help orientate the reader.

3.4.2.3 Structure and sequence of sections in Chapters 4-7

Chapters 4-7 will begin with a brief description of the themes and sub-themes covered in that chapter, and associated theme diagrams. In Chapters 4-6, this will be followed by a presentation, analysis and summary of the findings related to the asthma group, which is repeated for findings relating to the diabetes group. A consideration of similarities and differences in the findings of the two groups will then be included, to highlight any illness-specific findings, followed by an overall summary. Theme diagrams will be used as described in the previous section. Interview extracts will be used throughout, to provide evidence

supporting reported findings. Further evidence in the form of indexed data is offered in the appendix in the form of tables associated with each of the empirical chapters. Chapter 7 has a slightly different, abbreviated format, which is explained in the Chapter introduction.

All empirical chapters will conclude with a discussion of the overall findings in the context of the research objective(s). Key insights will be presented, and elements of the theoretical model that relate to the chapter findings will be presented. Schematic diagrams will be used to represent key findings and relationships relevant to the theoretical model.

Chapter 8 will draw together the chapter findings and discuss them in the context of the study objectives. This Chapter will also include a presentation and discussion of a set of theoretical propositions (as illustrated in the schematic diagrams), some over-arching themes and a theoretical model. Implications for future research, theory and practice will be discussed.

3.4.2.4 Schematic diagrams and representation of related symbols

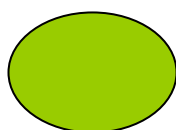
Schematic diagrams are used at the end of each empirical chapter to illustrate different aspects of the parents' and family members' experiences and relationships between various factors that appeared, from the data, to influence adjustment. The symbols shown below are those used within these diagrams to represent events, thoughts and emotions, actions and outcomes. Types of notation will be used to indicate where evidence for relationships between different aspects of parents' perceptions and experience have been clearly demonstrated or are hypothesised. Different colours and symbols will be used to add clarity, as follows:



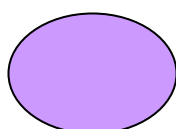
= an event (e.g. needle-related procedure), or external entity (e.g. availability of professional support)



= a perceived 'state' of the parent, child or sibling, e.g. young age






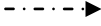


= the parent's reported emotions, thoughts or beliefs



= the parent's reported actions

-  = representing combined parent emotions, thoughts or beliefs and their behaviour
-  = the child's reported emotions, thoughts or beliefs
-  = the child's reported actions
-  = where both parent and child have similar emotions, thoughts or beliefs
-  = where both parent and child have similar reported actions
-  = where there is a hypothesised emotion, thought or belief of parent or child
-  = parent report of actions of doctors or people outside the family
-  = sibling's reported emotions, thoughts or beliefs
-  = the sibling's reported actions
-  = pink border, irrespective of central colour, signifies a particularly important influence or end point
-  = indicates a group of influential factors

-  = comments or descriptive information
-  = influential relationship for which there is some evidence from the data
-  = influential relationship for which there is stronger evidence
-  = where there is an interactive relationship
-  = (any colour) where there is a specific influential relationship that only applies in a certain case (i.e. follow the direction of the specific colour)
-  = where there is a hypothesised influential relationship (i.e. no direct evidence from the data)

3.5 SUMMARY

This chapter has outlined the aim and objectives of the research study, and reported and discussed the method adopted. The axiology, epistemology, ontology and methodology of the study were described, with rationale given for their choice. A grounded theory methodology was selected and justified on the basis of the research objectives. The use of thematic analysis as a data analytic tool was discussed, and the procedure outlined. In addition, methodological issues were considered, including those relating to the conduct of individual and joint interviews, the presence of children and the shared objectives served by the interviews. The outline of the final report was presented, which will provide a framework for reporting the results, the proposed theoretical model, and the final discussion.

CHAPTER 4: PARENTS' EXPERIENCE OF THEIR CHILD'S EMOTIONAL AND SOCIAL RESPONSES TO CHRONIC ILLNESS

4.1 INTRODUCTION

This Chapter will report the results arising from the thematic analysis of data from interviews of parents of children with diabetes or asthma. The specific focus will be on the three themes that relate to parents' experiences of the child's emotional and social responses to their illness. These themes are:

Child individuality of response - behaviour or emotion

Effects on child's social life

Child's relationships with friends, peers and at school

Following a brief explanation of these themes, results will be reported and discussed under the headings of these three themes. For each theme, the asthma group results will be described first, followed by the diabetes group results; group comparisons will then be made following each theme. At the end of this chapter, insights relating to the developing theoretical model will be presented based on the data analysis from this chapter. This will be revisited in later chapters.

4.1.1 Explanation of themes considered in this chapter

Child individuality of Response - behaviour or emotion

This theme was identified when it became apparent that parents attributed illness responses to a range of factors including their child's age, personality or unique biological functioning. Although three sub-themes of 'individuality of response' were identified (behaviour and emotion, managing treatment and physical responses and triggers), the latter two sub-themes will be discussed in Chapter 5, as they are more relevant to the theme about illness, treatment and precautions.

Parents referred to how physiological or environmental factors interacted with their child's unique individual characteristics (such as the child's personality, seasonal responsiveness to

environmental triggers for asthmatics, or rapid puberty changes for diabetics). Such factors were discussed by parents not just in the context of their child's everyday functioning, but also when describing their beliefs concerning how well their child managed, coped with or responded to treatment. They perceived that these individual factors influenced the child's physical symptoms or responses, which in turn affected their psychological and social responses. Many parents went on to offer explanations and discuss implications not only for the child's but their own adjustment.

Effects on child's social life

The second theme is different from the first, in that it relates to external rather than internal factors affecting the child. An example is whether or not a child attends (or is invited to attend) birthday parties or 'sleep-overs'. Some children attend, whereas others don't because the child and/or their own parents or the potential host parents are worried about managing an attack or the treatment away from home. Other examples of this theme are when children miss school or are unable to go on school trips because of illness or because school staff won't take responsibility for the child. This has significance for parental stress and coping, as many parents expressed upset (sometimes crying during the interview) because they felt they were unable to offer their child these experiences.

Child's relationships with friends, peers and at school

This minor theme relates to the child's friendship, teacher and peer experiences outside the family context. Some parents reported that their child had supportive friends and teachers who helped them to cope with the problems they were experiencing, whilst other children experienced bullying or social ostracisation. The child's social experiences with friends, teachers and peers were important to parents, who expressed positive feelings, for example when their child was able to be open with and be supported by friends, and sad or angry feelings when their child was bullied or excluded.

4.2 CHILD INDIVIDUALITY OF RESPONSE - BEHAVIOUR OR EMOTION

In this section of the chapter, the results of the analysis of first of the three sub-themes of '*Child's Individuality of Response*' will be presented (namely behaviour or emotion), firstly for the asthma group and secondly for the diabetes group. The behaviour and emotion components for the asthma group will be described under the following seven headings:

Child Individuality of Response - Behaviour or Emotion: Behaviour or emotions relating to hospitalisation or acute episodes

Child Individuality of Response - Behaviour or Emotion: Behaviour or emotions during clinic visits

Child Individuality of Response - Behaviour or Emotion: Disease / treatment-related behaviours (not treatment management)

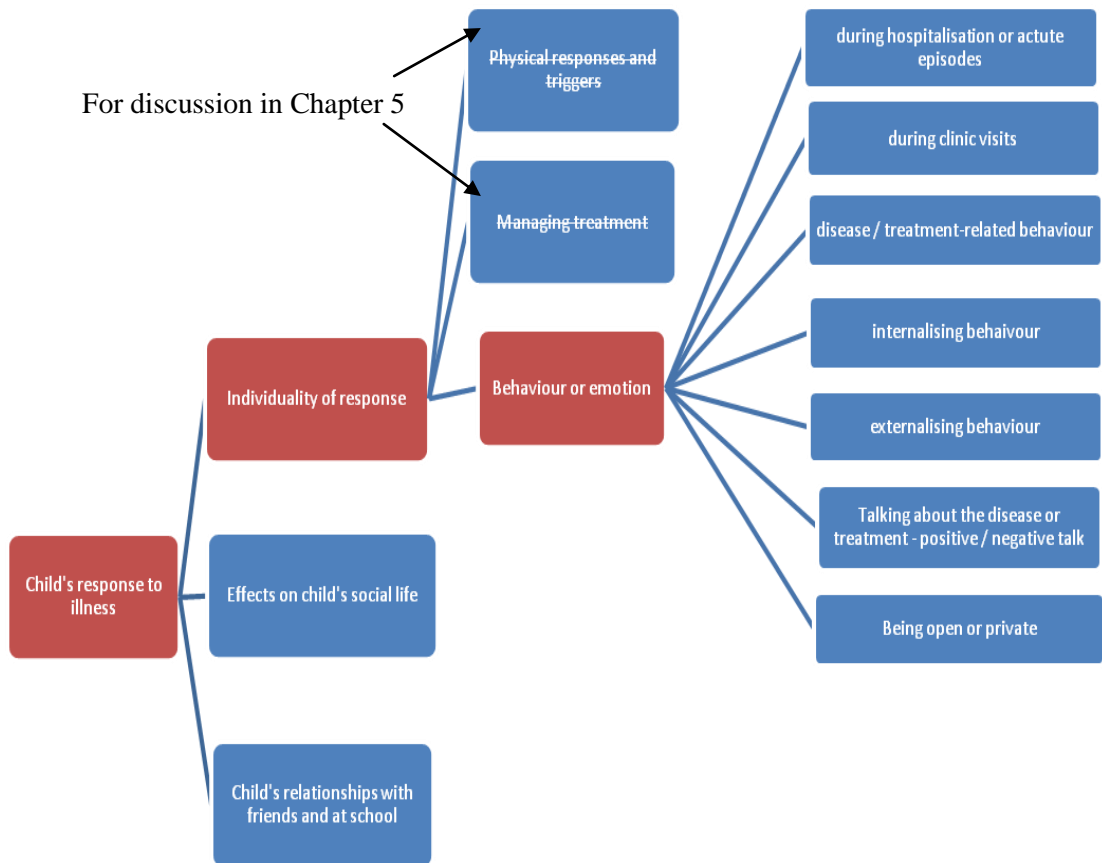
Child Individuality of Response - Behaviour or Emotion: Internalising behaviour (non-hospital)

Child Individuality of Response - Behaviour or Emotion: Externalising behaviour (non-hospital)

Child Individuality of Response - Behaviour or Emotion: Talking about the disease or treatment – 'negative' talk and 'positive' talk

Child Individuality of Response - Behaviour or Emotion: Being open or private about the disease or treatment

These aspects of the child's behaviour or emotion are illustrated in the following diagram (right hand side):

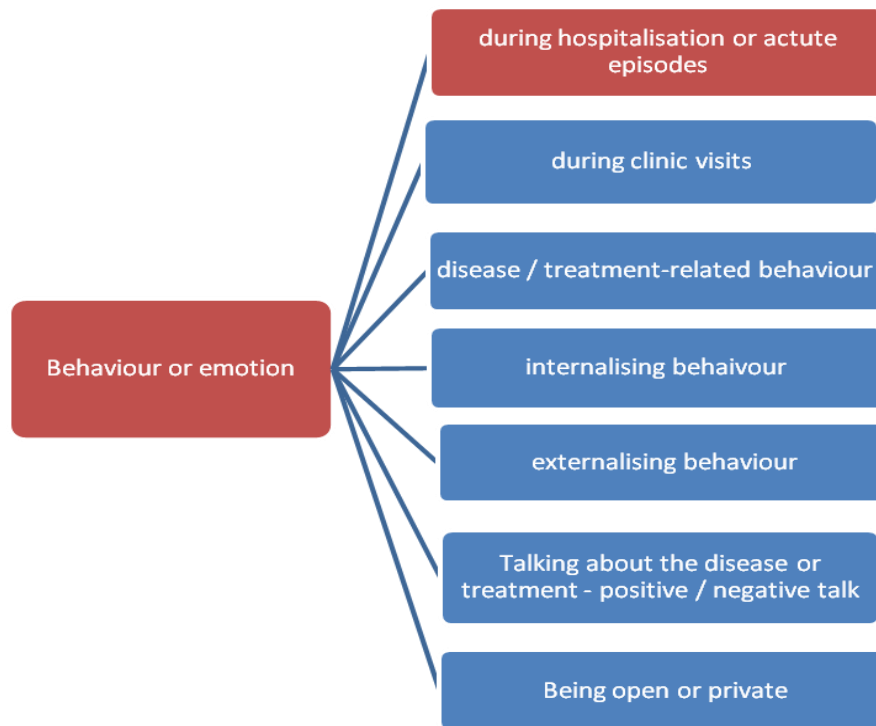


(N.B.: The two sub-themes, 'Physical responses and triggers' and 'Managing treatment' are crossed out, because the results will be discussed in Chapter 5).

As the number of participants was quite large and respondent reporting of child behaviour and emotions was extensive, illustrative examples of interview extracts will be presented within the narrative of this chapter. Reference will be made to data presented in tables in Appendices 4.1-4.6 on pages 26-63, so that further details about typical and atypical parental responses may be identified by the reader.

4.3 CHILD INDIVIDUALITY OF RESPONSE - BEHAVIOUR OR EMOTION: ASTHMA GROUP

4.3.1. Child Individuality of Response - Behaviour or Emotion: Behaviour or emotions during hospitalisation and acute episodes (Asthma Group)



This sub-theme related to children’s behaviour and emotions during hospitalisation and acute episodes. As responses during hospitalisation and acute episodes were similar, they will be discussed together in this section.

With one exception (A_10), where the child was not being followed by the hospital respiratory clinic, all children in this sample had experienced hospital admissions for asthma. Twelve parents in the sample described their child’s emotions and behaviour during these admissions and the parents’ own responses to the child’s behaviour. Some parents described behaviour and emotions of their child during ‘acute episodes’, for example asthma attacks at home that were managed with the support of the GP, and how they as parents felt about their child’s behaviour.

The following interview excerpts represent the three main types of behaviour or emotion reported by parents:

- a) Being accepting, passive or 'brave' (A_1, A_2, A_3, A_5, A_8, A_9, A_12, A_15, A_16).
- b) Being abnormally withdrawn or regressed (A_1, A_7, A_11, A_16).
- c) Being overtly anxious, panicky or uncooperative (A_2, A_5, A_7, A_8, A_8, A_11, A_14).

Child Individuality of Response - Behaviour or Emotion: Child behaviour or emotions relating to hospitalisation or acute episodes: Example - being accepting, passive or 'brave'

The mother and grandmother in the example overleaf described how their child / grandchild had experienced multiple (approximately monthly) hospital admissions for about six years, up to the age of about 8, and less frequently thereafter. The admissions had therefore become part of normal life, which the respondents believed partly accounted for the child's passive acceptance of hospitalisation. The parent of A_1 also commented that she thought her child's passive behaviour was due to getting used to the hospital experience.

Respondent	Interview extract
<p>A_15</p> <p>Accepting, passive or 'brave'</p>	<p>I: So you had six years nearly of nightmares really, of having to take him into hospital regularly, like once a month or so. That must have been very hard on your family.</p> <p>M: I mean, we had a bag pre-packed and it was a case of all the people that we knew at my work and my Mom's work, they knew that there would be a phone call. And that would be it. And it would be a couple of days. And I'd be sitting there doing work in a hospital room, and he would be bored out of his skull, yeah.</p> <p>.....</p> <p>G:... We tried to do it [visiting hospital] separately, so he'd have somebody seeing him practically all day, you know?</p> <p>M: Yeah. Although towards the end, as well, it didn't agree with one of us, so we wouldn't bother trying. He had his little asthma friends, and his nurses and sisters that spoiled him rotten, and he could take his own videos in and watch videos, and you know what it's like when a kid's in hospital? We'd buy him colouring books and tech Lego and all sorts. Towards the end he was quite happy to see the back of us.</p>

Other behaviours described by parents whose children were accepting, passive or brave included accepting treatment without protest (A_1, A_2, A_5, A_8, A_15, A_16), not saying how they felt (so perhaps being withdrawn) (A_16), being positive and accepting (A_9, A_12), staying calm / not panicking during an attack (A_8, A_12), and making jokes with staff – putting on a brave face (A_16). Parents generally viewed their child's behaviour as positive and were proud of the way their child handled the hospital experience.

The explanations that parents offered for their child's passivity and acceptance included that they had become accustomed to the treatment (A_2) or were too ill or lacked energy to object to interventions (A_1, A_3, A_5). Other parents (A_1, A_8, A_9, A_12, A_15) talked about how their child's temperament contributed to this accepting behaviour. For example, the parents of A_8 thought their child wasn't stressed in hospital because he was articulate in communicating his thoughts / feelings to hospital staff and was well supported by the staff because of his charming manner.

Child Individuality of Response - Behaviour or Emotion: Child behaviour or emotions relating to hospitalisation or acute episodes: Example - being abnormally withdrawn or regressed

Parents of four children described their child's abnormally withdrawn or regressed behaviour in hospital (A_1, A_7, A_11, A_16). This included altered talking, playing, eating or toileting (A_1, A_7 and A_16), being 'clingy' and not wanting the parent to leave (A_11, A_16) and being upset, restless or wakeful (A_7). Generally, these behaviours were reported in younger children who were aged 4, 5 and 7 and a child who the parent described as autistic, aged 10.

In this example, the child displayed altered behaviour, which the parent perceived as being abnormal and of concern. This child was the one reported in section 4.3.1., where the parent attributed subsequent sleep difficulties to a hospital admission.

Respondent	Interview extract
<p>A_16</p> <p>Pre-school boy</p> <p>Abnormally withdrawn or regressed</p>	<p>M: Well [hospital], it's a different environment, and the mask.</p> <p>I: He doesn't like the mask being put on him.</p> <p>M: He gets, he doesn't cry, he just gets so...he doesn't get rest....he gets restless. I think it's the whole thing, and he's like holding my neck.</p> <p>We keep going to the same ward, in the same bay, and there's this poor little girl. She never left the hospital, and she must be about three. She's got a tube going in her neck, and she's always there. We feel so sorry for her. It just makes me so upset, and you stay there all the time, sad. Sad.</p> <p>I: It's hard for [child's name] to see her as well.</p> <p>M: Yes, I think we try to begin to talk, to speak, to play with everything, and I think he feels a bit, he does notice.</p> <p>I: A bit strange for him.</p> <p>M: Yeah, must be, isn't it? Yes. I think that's what [husband's name] said. Don't insist, just sit with him and play with him because he doesn't know.</p> <p>I: I know. But he doesn't actually get acutely distressed, he doesn't actually cry.</p> <p>M: Crying, no, no. You see he's not in his right being, but he doesn't cry or anything. He's just not the way he is. You know.</p> <p>...I: He's not himself, really.</p> <p>M: No. And we have to have a shower in the shower, and it's all difficult really. So I just hope we don't have to go in.</p>

Child Individuality of Response - Behaviour or Emotion: Child behaviour or emotions relating to hospitalisation or acute episodes: Example - being overtly anxious, panicky or uncooperative

In this section, the reports of the parents of A_7 and A_9 are used to illustrate parental reports of their child's occasional anxious, panicky or uncooperative behaviour, which was reported in five other interviews (A_2, A_5, A_8, A_11, A_14). Often (and sometimes exclusively) this was in relation to needles. The parent of A_7 expressed anxiety herself about needles, which may have exacerbated her child's fears:

Respondent	Interview extract
<p>A_7</p> <p>School aged girl</p> <p>Anxious, panicky or uncooperative</p>	<p>I: How does [child's name] react when she goes into hospital?</p> <p>M: She hates it. She's scared. Won't cooperate at the best of times. Doctors tell her to sit up when they want to listen to her chest. She will not move. So she takes a lot of coercing from me to get her to... bribery.</p> <p>I: Does that work? Bribery?</p> <p>M: Bribery does. Like, 'If you do it, then I'll go down to the shop and buy you a book or something'.</p> <p>I: So, [child's name], when she does get upset, how do you respond?</p> <p>M: I cuddle her and try to reassure her that it's OK, the hospital are doing these tests to help her. They have to do them; she's not the only child that has to have these tests. There's a lot of little children that, a lot smaller than [child's name], that have these problems.</p> <p>I: Do you think you did anything or said anything that helped you in those situations?</p> <p>M: I just kept drumming it into me own head to keep calm, I think. Constantly beating myself up about it - 'You've got to stay calm for her. You've got to stay calm, stay focused, relax, and concentrate, because [child's name] is the priority. And if she sees you upset, she's understandably going to be upset herself. So, just try and stay calm'. And it has worked. Admittedly, it has worked. The only thing I don't like is when they have to take blood from her, because I'm needle phobic. I'm scared of needles. All my children - anyone come near me with a needle, I nearly pass out. So... that's the one part I don't like. And that's the bit where I do go, 'Oh my God!' big breath and I have to walk out the room. I can't stay with her for that bit. That part, she has to be on her own for, well, with the doctors and the nurses.</p> <p>I: How does she find it?</p> <p>M: Distressing. Which makes me feel even worse. I don't want to leave her but I can't handle needles, and to see them jabbing them in my children, I get very angry and stand there with my fist clenched. And I shouldn't, but it's just an automatic reaction, because you think it's hurting your children and you know it's for the best, that they've got to have it done, but I still really - I'm not a fan of that.</p>

This respondent perceived that her child's anxiety was the basis of her uncooperative behaviour during a physical examination. The parent's own fears of needles made it more difficult for her to support her child at these times, which caused her some degree of guilt. In contrast, another parent (A_2) discussed how she addressed her child's needle-related fears by actively modelling appropriate behaviour with needles (when the mother was having blood

taken). She believed that this would show her son that he did not have to be frightened of needles.

Other reasons offered by parents for their child’s uncooperative behaviour included finding the noise of the nebuliser and mask distressing when younger (A_14), or lack of understanding of what was happening, due to their young age (A_2). Whilst the parents of both A_7 above and A_14 reported feeling frightened and concerned in some treatment-related situations when the child was uncooperative, respondent A_14 said she was firm with her child to encourage cooperation, whilst respondent A_7 bribed her child.

Whilst some children (particularly younger ones) showed more extreme distress, older children tended to be able to control their anxiety more effectively. Furthermore, the younger children (as in the excerpt above) were more dependent on parental support to cope, whereas for older children, the parents’ supportive interventions were less strongly significant. For example, in the case of A_9, the parent reported that although her son felt anxious about blood tests, he coped quite well, with less need for parental intervention:

Respondent	Interview extract
<p>A_9</p> <p>Anxious, but cooperative</p>	<p>M: He didn’t like the needles. He didn’t like the blood tests. He was so unwell when he first went in though, that he couldn’t really, I mean he was vomiting and everything, and he just couldn’t really complain about anything.</p> <p>I: No, no, but the blood tests, when he was a bit more alert, how did he respond to those?</p> <p>M: Well, he kind of looked away and screwed his face up and he really didn’t want it, and he wanted somebody there with him all the time that it was happening. But he was pretty good.</p> <p>I: And you were there with him?</p> <p>M: I was there when I could be, or my husband, or somebody was there with him, yeah.</p> <p>I: And he found that quite reassuring.</p> <p>M: I think so, yeah.</p>

4.3.1.1. Summary of children's behaviour or emotions relating to hospitalisation or acute episodes and parent responses (Asthma Group)

In summary, some types of child behaviour were generally regarded in a positive light (i.e. being accepting, passive or 'brave'). Parents did not suggest the possibility that this behaviour (except perhaps in the case of A_16) might be related to anxiety and withdrawal. They tended to attribute this behaviour to the child's compliant temperament, their previous hospitalisation history (e.g. 'have gotten used to it') or because they were too ill to protest. Generally, parents did not report that they needed to intervene where such behaviours were exhibited.

One group of behaviours that parents viewed with concern were where the child was abnormally withdrawn or regressed. These tended to be described in younger children in the sample; the kinds of behaviour affected were talking, playing, eating, sleeping or toileting, where they exhibited some regression, and being 'clingy' and not wanting the parent to leave, or being 'restless'. Parents tended to respond by physically comforting and talking to their child and trying to preserve normality (e.g. encouraging play).

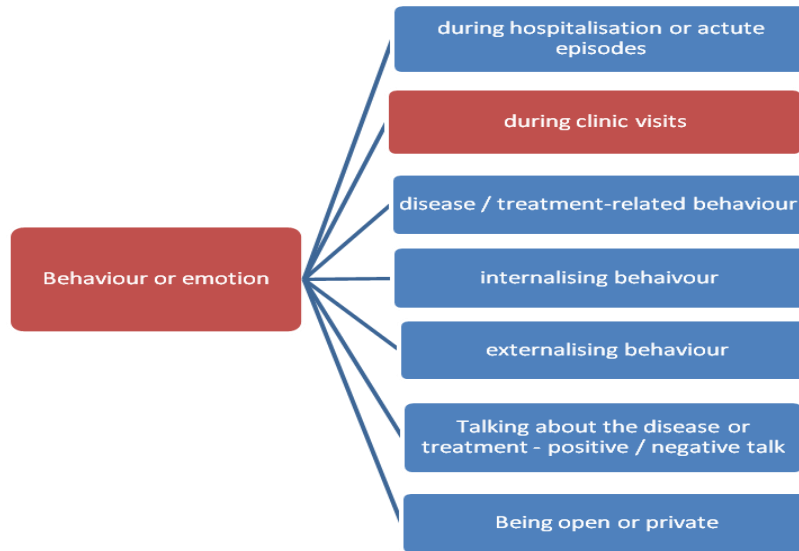
More commonly, parents reported overtly anxious / panicky or uncooperative child behaviour. Most commonly, this was only in relation to specific circumstances (e.g. needle-related procedures). This kind of behaviour was reported across the full age range of the sample. However, the younger children in the sample were less able to control their anxiety and distress, and were more reliant on parental support. The parents of younger children felt more compelled to take supportive action, although in the case of A_7, the parent's own anxiety about needles prevented her from offering this support, which contributed to her feeling guilty.

4.3.2. Child Individuality of Response - Behaviour or Emotion: Child behaviour or emotions during clinic visits (Asthma Group)

Seven parents described their child's behaviour or emotions during clinic visits, much of which centred on the nature of communication with clinic staff and parents. The children in this sample (with one exception) were followed closely by a hospital clinic, attending every three to six months, or more often following recent hospital admissions. In the one exception (A_10), the child was followed on a regular basis by the asthma nurse and GP at the local health centre. Seven parents described their child's behaviour whilst at clinic, much of which centred on emotions such as anger or feeling reassured, and behaviours relating to

communication. Two types of child behaviour were reported by parents during clinic visits, some of which were exhibited at different times by the same children:

- a) Being angry, upset or uncommunicative (A_5, A_10, A_13 and A_15)
- b) Being cooperative, seeing the positive side (A_3, A_9, A_11, A_13, and A_15)



Child Individuality of Response - Behaviour or Emotion: Child behaviour or emotions during clinic visits - Example of angry, upset or uncommunicative behaviour

In the following extract, the parent of an adolescent with a long history of poorly controlled asthma describes his feelings of upset about coming to clinic and finding that he is not getting any better. The parent, who also feels these things, expresses these feelings in more detail:

Respondent	Interview extract
<p>A_5 Adolescent boy</p> <p>Being angry, upset or uncommunicative</p>	<p>I: So, it sounds like when you say you're not feeling as positive, it's when you come to clinic, it seems to be one of the difficult times for you.</p> <p>M: Yeah, because you always think, when you come to clinic, they'll say, 'Oh, he can come off that, and it is better', and of course there's no miracle cure, and it's not better. But I think that's the reality of it, that you always think there's going to be a miracle tablet, and you're going to come one day and there's going to be a miracle tablet, and you're going to have another couple of months of good time, but with [child's name's] asthma, you don't get that because he plummets back down again as quick as you think, 'Oh, it's getting better', and then it plummets. So...</p>

	<p>...I: So what would you say was your biggest concern at the moment in relation to [child's name]'s asthma?</p> <p>M: Um, it's just really, his, as a child, him trying to understand why he's on certain stuff for certain reasons and when he gets older, he can understand, he can balance out the reasons, but while he was growing up he couldn't balance out why he's on certain stuff, he didn't understand. He just thought of his doctor's [at clinic] being awkward, or it's not fair on him. He didn't understand stuff.</p> <p>I: So that was a concern then. Do you think that's different now?</p> <p>M: As he gets older, yeah, he's understanding more.</p> <p><i>Later in the interview, the parent described how each time of coming to clinic, she and her son hoped that a milestone would have been reached:</i></p> <p>M: Yeah, yeah, you have to look like that, look forward to a milestone, like you say, and see when you get there. But when you get there and it's still the same or he's had more, then you'll be looking at, here we go, we've got another seven years of this, so...</p> <p>I: How does that make you feel, really?</p> <p>M: I feel, as because [child's name's] going to be an adult soon, it's going to be his burden then, because it takes it off you so much, because he's an adult and he's going to go. Obviously, he's going to leave home at some point, and he's got to take it on board, and I feel sorry for him if it's not going to get any better but he's taking that all on board as an adult, on his own, and that hurts to think that. Because at the moment he's pressured, alright, he's upset today, but he's got me to sit there and ask the questions and guide him through it and tell him what is on. But soon, it's going to be him that's got to do all that.</p>
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A difficulty in an adolescents' communicating in clinic interactions was also reported by the parent of A_10, who said her son just 'grunted' when interacting with health professionals, which she attributed to his stage of development. Another parent (A_15) reported that her adolescent son did not like to tell doctors at clinic that he hadn't been taking his medicine. Finally, the youngest child in the sample (aged 2) was reported by parents to be starting to object to coming to clinic and exhibiting some protest at being examined, except when with a parent. They considered that this was related to developmental changes in his awareness and ability to anticipate the nature of clinic experiences. These parental explanations are child-focused, i.e. related to the child's characteristics (developmental stage) or in relation to prior experience and treatment.

Child Individuality of Response - Behaviour or Emotion: Child behaviour or emotions during clinic visits - Example of cooperative behaviour and seeing the positive side, and parent response

Many of the children did not object to coming to clinic, and some quite enjoyed having time off school or being able to have time alone with the parent (A_3, A_9, A_11). One parent said her child found the clinic reassuring (A_15) and another that they enjoyed some aspects of it, such as doing the peak flow (A_11).

The following example illustrates how children often felt positively about attending clinic:

Respondent	Interview extract
<p>A_11</p> <p>Cooperative, seeing positive side</p>	<p>I: And clinic. How do you feel about that, you and [child's name] feel about that?</p> <p>M: Alright. It's like an afternoon out, isn't it? (laughs)</p> <p>I: So you don't mind it and he doesn't mind it.</p> <p>R: No. No. He likes blowing into that thing, like bubble gum. [peak flow meter to assess lung function]</p>

The timing of the clinic (at the same time as school) meant that this offered a welcome change for a number of children. Another parent (A_15), whose son generally enjoyed the clinic, found it reassuring as he trusted the doctors who he thought were more competent than previous doctors he had seen outside the hospital.

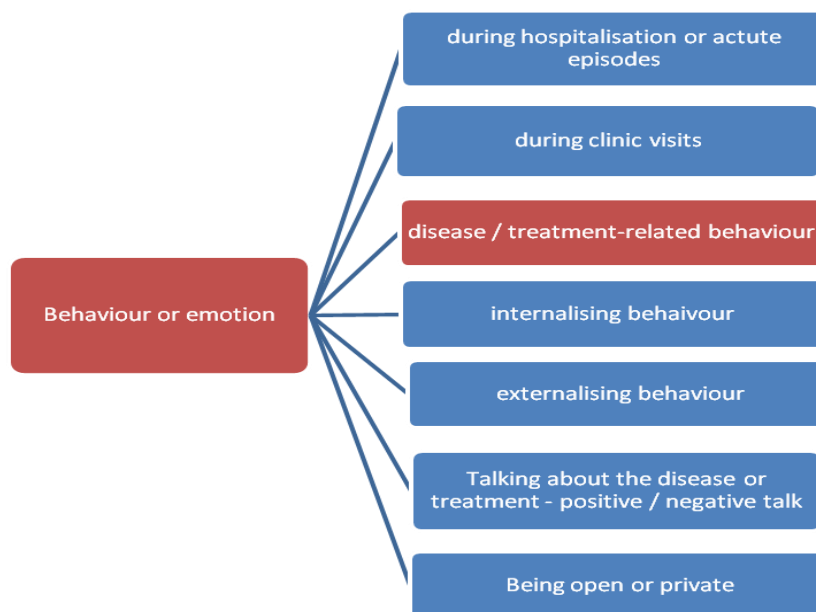
4.3.2.1. Summary of children's behaviour or emotions during clinic visits and parent responses (Asthma Group)

Clinic visits were viewed positively by most children and parents. Many children saw clinic visits as a 'day out' or a chance to be off school; for others it was reassuring or offered opportunities to participate in asthma assessments. Only one parent said her child expressed anger and upset (A_5). Other more negative child behaviours reported were the child not communicating well with clinic staff, and disliking the doctor saying they should take their medicine.

4.3.3. Child Individuality of Response - Behaviour or Emotion: Disease / treatment-related behaviours (Asthma Group)

This sub-theme relates to some aspect of child behaviour associated with treatment, but not including the behaviours and feelings associated with taking medications and measuring peak flows. These data were instead coded under ‘treatment management’. The reason for reporting these behaviours separately, in the next section, is that ‘treatment management’ always involves some kind of parent-child interaction (such as negotiation) about treatment, whereas many of the behaviour and emotions coded under the present sub-theme only related to child behaviour. These included:

- a) Minimising the focus on the disease or treatment (trying to be ‘normal’) (A_4, A_5, A_6, A_7, A_8, A_9, A-16)
- b) Avoiding attacks or not (A_2, A_5, A_8, A_14)
- c) Using illness (A-5)



Of these three types of behaviour and emotions, those most commonly reported related to minimising focus on the disease or treatment. These behaviours included the child trying hard at school or play despite health problems (A_4, A_6, A_8, A_16), doing ‘normal’ things without considering the health consequences (A_5, A_16), and not telling the parent when they were becoming unwell (A_5, A_6). One child chose to take up new activities that, although motivated by wanting to do things with his friends, were also beneficial to his health – rugby training and playing the trumpet (A_9). Finally, parents of two children expressed

that the child didn't mind the physical restrictions of asthma (A_7, A_8). Common to all of these types of behaviour and emotion is the child's desire to emphasise normality. Most of the time, parents viewed this in a positive way, although less commonly did so when the consequences of the behaviour resulted in exacerbations of health problems, such as exercise-induced asthma attacks.

The child's wish to maintain normality by minimising the focus on the disease was sometimes connected with their wish to avoid risks of attacks or deny risks or symptoms. Some children avoided attacks through not exerting themselves at sport (thereby not exhibiting symptoms that would be noticed by others) or ignored risks of attacks. For example, the daughter of A_4 carried on with competitive sports even though it made her ill.

Where the child avoided risks (e.g. active sports), they sometimes accepted the situation as they didn't mind restrictions (because they weren't 'sporty'). In common with the examples above, parents generally supported and encouraged their child's attempts to avoid attacks; more 'risky' behaviours associated with normal activities (like engaging in active sports) were also supported, except where the child's health was at risk. An exception was the parent of A_4, who saw in a favourable light her child's persistence at sports despite the resultant exacerbation of symptoms; she viewed her child as 'gutsy' and having a positive attitude.

It's possible that the attitude of the parent about what is important for their child's development influences their perceptions of the child's behaviour. For example, if maintaining good health and avoiding attacks is viewed as important, they might be anxious about their child's engagement in active sports. On the other hand, if they perceive that being 'normal' and having good social development opportunities is most important, they might be less concerned about their child experiencing asthma symptoms (as in the case of A_4).

Child Individuality of Response - Behaviour or Emotion: Disease / treatment-related behaviours: Example – being normal / not avoiding attacks

In the following example (child of A_5), there is some overlap between the groups of behaviours (a) and (b) above, in that the child is trying to be 'normal' by stroking the horse like his friend did, but through doing this, has engaged in 'risky' behaviour that has triggered an asthma attack:

Respondent	Interview extract
<p>A_5</p> <p>Minimising focus on disease (being normal)</p>	<p>M: ..And then his friend said to me, ‘Do you think it was that horse he was stroking that got him that bad?’ And I said, ‘What horse?’ And he said, ‘Well, we were stroking a horse the day he came into hospital’. And that’s when I went mad. I did not realise that [child’s name] had touched a horse, and [child’s name] said, ‘Oh, I just wanted to touch it because I liked it, and I wanted to stroke it’. And honestly, he’d reacted straight away, and I had no idea he had touched this horse on his way home or whatever! (Laughs). And that’s why he was in hospital that day. But three days later, I only knew about it, but of course he was frightened to tell me and like a little child, he wanted to touch it, and he did touch it, and he paid the consequences of touching it, so... That was a sort of, not funny, but the way it came about was.</p> <p>I: It’s difficult though, isn’t it, when you can’t do things that other children can do.</p> <p>M: Hmm. He was with this little boy and the boy wanted to stroke the horse. He wanted to stroke it, and he didn’t think it would do any harm.</p>

The parent above believed that her child, possibly because of his young age, did not realise that touching the horse would trigger an attack. Perhaps this made the parent more tolerant and forgiving of her child, but may have increased her concern about his trustworthiness to avoid future attacks.

Where parents indicated that their child behaved in ways that didn’t trigger attacks (e.g. related to avoiding physical exertion), they said this was that because of their child’s beliefs about what could stimulate symptoms (A_8, A_14, A_7). One couple (A_8) said their child avoided symptoms by choosing friends he could trust to help him avoid risks and manage attacks; they believed this was possible because their son was a good judge of people, which increased their confidence in the child’s safety. However, the parents also felt that the child avoided taking responsibility himself when going without a parent in high risk situations (in this case, a sweet shop where there could be allergens to which he was sensitive). They believed that at age 12, he did not yet feel ready to think about the possibility of having an anaphylactic reaction, or independently deal with the consequences of this in such an environment. The parents felt this limited their son’s ability to take part in some normal activities (like going to a sweet shop with friends).

Where a child did undertake activities, particularly those involving physical exertion, parents said it was because the child wanted to keep up with their friends or be like their friends (A_9, A_15). Where these activities did not actually result in health problems (as in the case of

A_9), the parent was very pleased that they were able to be ‘normal’. However, this was not necessarily true where the consequence of engaging in sports was the worsening of symptoms. In the case of A_15, the symptoms were often so problematic that the child was unable to function in a sports team; in this case, the child and parent both experienced sadness and disappointment. Although the child of A_4 also became ill when engaging in such sports, it seemed that she was still able to function, although not optimally. Thus, the nature and severity of asthma symptoms appears to influence both the child’s behaviour with regard to avoiding attacks and the parents’ perceptions and responses.

Finally, one parent (A_5) described how her child, when younger, deliberately made his symptoms worse to make the parent stay with him at night or to remain with him in hospital. The parent evidently felt her child was ‘using’ the illness to achieve this objective. She however felt like a ‘bad’ parent when giving in, and also felt guilty about consequently giving less attention to her other children.

4.3.3.1. Summary of disease / treatment-related behaviours

Most of the behaviours described in this section were, according to parents, related in some way to the child’s wish for a ‘normal’ life, and to ‘fit in’ with friends. There was a desire by many children not to focus on the disease or treatment and to do things that other children do. In general, the parents encouraged these efforts, although not in some cases where they believed this was detrimental to the child’s health. The perceptions and behaviour of the parents may be influenced by a number of factors:

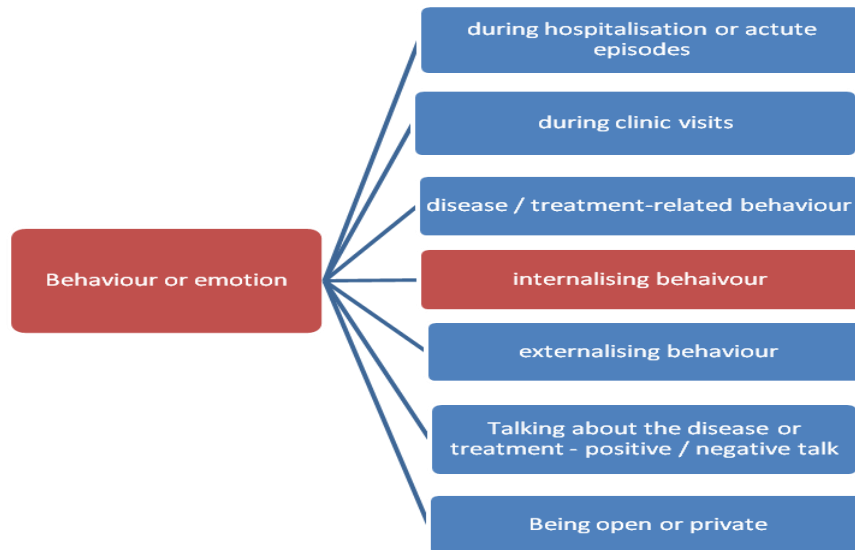
- the severity of the child’s illness (i.e. how unwell the child was likely to get and whether they could actually function if participating in active sports)
- individual child characteristics, such as their developmental ‘readiness’ to take personal responsibility for avoiding attacks (i.e. whether or not they had the emotional and cognitive maturity to deal with risky situations on their own – e.g. with animals or in a sweet shop)
- the attitude and beliefs held by the parents about what is most important for their child’s development (i.e. for their child to maintain ideal health and avoid attacks, or to have normal social development opportunities).

The above factors could influence the degree of parental stress. For example, the parent of A_5 felt as sad and disappointed, as was her son, at his inability to participate in sports; the parents of A_8 expressed some anxiety about their son's wish not to take responsibility for his Epipens (adrenaline injection to be given in case of an anaphylactic / allergic reaction), so leading to him missing out on activities such as visiting a sweet shop with friends. In common with points made in previous sections, individual characteristics of the child, such as being a 'good judge of people' (A_8) or 'gutsy' and 'positive' (A_4) influenced the degree of anxiety the parents felt when the child engaged in possibly risky behaviour.

4.3.4. Child Individuality of Response - Behaviour or Emotion: Internalising behaviour (non-hospital) (Asthma Group)

It was unusual during the interviews for parents to describe their child's emotions in depth; they tended to describe behaviour, some of which was internalising (such as withdrawing from social interactions and sleep disturbances). Typically, parents spontaneously discussed what they believed to be the origin of the child's feelings and/or behaviour. Sometimes this was very focused on their child's attributes (such as their temperament, personal characteristics, habits or developmental age), and at other times their child's characteristics in interaction with particular illness experiences or illness features. In turn, this related to any direct action that the parent chose to take in response to the behaviour. For example, if the behaviour was largely linked to the child's unchangeable personality, characteristics or self-concept, the parent tended not to feel able to control it, leading to feelings of helplessness. More typically, parents saw their child's behaviour as being caused by their child's characteristics in interaction with their illness itself or illness-related experiences or treatments.

The following two examples were selected as illustrative of internalising problems reported by parents, and include the parents' own responses to this behaviour. The first example is of a child who expressed feelings of depression (A_5), and the second is of a child who had sleep disturbances (A_16). Whilst the first example was the only reported instance of this behaviour in the asthma group, disturbances of sleeping or eating (A_5, A_12, A_8) or withdrawn or avoidant behaviour, for example in school situations (A_1, A_6, A_15, A_8) were more commonly reported. Appendices 4.1 and 4.2 include further information about these examples.



Child Individuality of Response - Behaviour or Emotion: Internalising behaviour (non-hospital): Example – depressed feelings

This parent attributes her child’s behaviour to her son’s asthma in interaction with his self-concept; the parent tries to speak positively, but finds this difficult.

Respondent	Interview extract
<p>A_5 Expresses depressed feelings</p>	<p>M: Um, [child’s name] finds it very, very hard sometimes, and we have been through states recently when he’s got really bad, that he didn’t want to live, and he was like, saying, ‘I don’t want to live with this any more. Why is it me? Why have I got it? It’s not fair. The two girls haven’t got it. Why have I got this?’ So he was very bitter. But it’s very hard to sit him down and say, ‘No, we can get over this [child’s name]. We can get medication to treat you, and you will be fine’. But as a sporty child as well, that’s where he finds it really hard, and with his peers at school, he finds it difficult to cope with.</p>

In this example, the parent feels somewhat helpless in supporting her child, perhaps because she is unable to improve his health. Also, she believes that seeing himself as a sporty child, he finds it more difficult than other children in his situation.

Child Individuality of Response - Behaviour or Emotion: Internalising behaviour (non-hospital): Example – sleep difficulties

This parent attributes her child’s behaviour to asthma, asthma history and medications, in interaction with child’s characteristics; the consequence for the parent was losing sleep and feeling unable to stop the sleep problem.

Respondent	Interview extract
<p>A_16</p> <p>Pre-school boy</p> <p>Sleep difficulties</p>	<p>M: He’s been waking up since December; he went to hospital. He’s been waking up every night. [Interview was in May].</p> <p>I: Every night?</p> <p>M: Yep.</p> <p>I: Since December?</p> <p>M: Since December.</p> <p>I: Oh dear.</p> <p>C: Well, sometimes I sleep at night.</p> <p>M: Yes, two nights ago you slept, he gets his stars.</p> <p>I: Oh, you get stars! That’s if you sleep in the night, is it?</p> <p>C: (Shows me his stars).</p> <p>I: That’s good. Those are nights when you slept? Oh, that’s good.</p> <p>M: Yes, they were good nights. You’ve got a lot.</p> <p>I: So that’s more recently you’ve done better, haven’t you? So when the weather’s a bit warmer, he does a bit better, or is that...?</p> <p>M: Well, it’s not related to the weather, because we took off for a while his medicine that Montelucast, it’s a blocker, it’s...I can’t remember now what it blocks, but it gives psychotic dreams, and he was waking up screaming and it was making him irritable and it was awful. So we stopped it. And then after we stopped, he slept for two nights, and three nights after the first stop. But then he started waking up again. But he had two nights last week, didn’t you? Yeah. But last night he did not, because he was coughing.</p>

The sleep problems of A_16’s child started after his discharge from hospital, following treatment for an asthmatic attack. The parent described later in the interview how her son had been emotionally disturbed by being in hospital, and thought this was the reason for his night waking, as this had started following discharge. She took it in turns with her husband

to get up and see to him. In addition to continuing to not sleep well, he sometimes wanted to sleep in their room during the night. She attributed her son's psychotic dreams to a drug he has been prescribed, but found that his night waking had not resolved following stopping the drug.

The parents attempted a reward system to encourage their child to sleep through the night, and this had been partially successful. Although a reward system was used (implying an assumption that child had the ability to consciously change his behaviour), the parent still attributed the sleep problems to factors outside her son's control (emotional disturbance due to hospitalisation, side effects of a drug). However, during the interview, the respondent expressed that she and her husband had difficulty in knowing how to deal with it, but hoped that he would grow out of it eventually.

4.3.4.1. Summary of children's internalising behaviour and parent responses (Asthma Group)

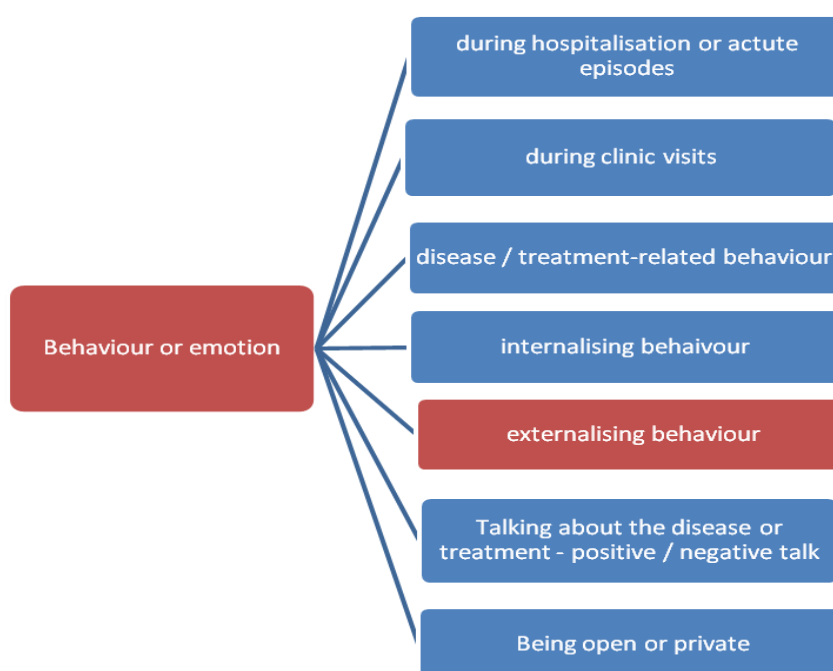
Overall, the seven parents who reported internalising behaviour of their child attributed this in some way to the child's asthma or asthma history, often in interaction with personal factors (e.g. developmental age or individual characteristics) and sometimes the parents' own behaviour. In general, the parents in this sample did not feel they were able to affect their child's behaviour significantly. This may be explained in part by the parents' beliefs about the causes of their child's difficulty, which were often considered by them to be uncontrollable. For example, children's attributes, age, asthma (which was often quite severe and not well controlled) or asthma history are not things that parents feel able to control.

Features of uncontrollable factors are that they are 'global' (i.e. applying widely – such as being a teenager, which is associated with moody behaviour) and 'stable' (i.e. lack of change in the disease severity). The consequence for individual parents included physical effects (e.g. sleep disruption due to child's night waking) and emotional effects (e.g. finding it hard to respond to child's depressed feelings). These experiences may contrast with those of parents of children without asthma, who may feel more able to alter their child's behaviour. For example, in the absence of symptoms (coughing) and drug side effects (psychotic dreams), the parent of A_16 may well have been successful in managing her child's sleep problem using the selected behavioural management technique of giving rewards for non-waking nights.

4.3.5. Child Individuality of Response - Behaviour or Emotion: Externalising behaviour (non-hospital) (Asthma Group)

This section relates to parents' responses about their child's externalising behaviour (such as angry and oppositional behaviour). Similarly to internalising behaviour discussed above, parents not only described their child's behaviour, but tried to explain it – including why it might have been worse because of the asthma or asthma history. They frequently discussed the impact of the behaviour on themselves as well.

The most commonly reported form of externalising behaviour was being 'stroppy' (argumentative), stubborn, angry, or oppositional (A_2, A_3, A_6, A_8, A_14). Other parents reported their child denying being unwell (A_6), being 'manipulative' (A_14) and being 'wacky' in appearance (A_6). Appendices 4.1 and 4.2 include further information about these examples.



Child Individuality of Response - Behaviour or Emotion: Externalising behaviour (non-hospital): Example – aggression

The following example was selected as illustrative of a typical group of externalising behaviour, namely being angry, aggressive, stubborn or oppositional. This parent attributed her child's behaviour to his asthma and treatment, in interaction with his characteristics (developmental age); the consequence for the parent was difficulty managing his aggressive behaviour.

Respondent	Interview extract
<p>A_2</p> <p>Pre-school boy</p> <p>Aggression related to multiple causes - anger and frustration about treatment, restricted activity and young age</p>	<p>M: But as I said, the majority of time he's very good. He does then get to the stage when he doesn't want it [mask with nebuliser] ON (said in aggravated voice), because he's feeling better in himself. But he does then start to get a bit ratty, because he wants to be up. When he's feeling a lot better, he wants to be up doing things, running around. You've got to try and say, 'No, you can't do that yet. You're going to have to keep calm for a bit longer'. And it does get frustrating for him. ... And he can lash out and get almost to the point of getting nasty. But it's understandable when he's getting frustrated. I remember one incident where he wanted to go outside and play outside, but I'm still wheeling around the oxygen to take with me. So I said, 'No, you can't.' Wheeling that around, carrying him around because, you know, I can't remember how old he was, he wanted to go outside and play! 'No, you can't.' And he just grabbed hold of my necklace at the time, pulled it and actually snapped the necklace because he was so frustrated. Well, he was feeling better, but he still wasn't.....It just tends to be when he's feeling better, that's when he starts to get, 'Don't want it on'. But you've got to have it on. That's when you have to start having to argue with him, 'Now, you keep it on..you know..uuhh'..... And it is hard, as I said, because when it's a young child as well, they cannot communicate to you too much about how they're feeling.</p>

This parent felt that her child's aggressive behaviour was related to the boy's frustration at restrictions in his activity and his reduced ability to communicate feelings at age 4. She saw her child as naturally hyperactive (also observed during the interview!), possibly further exacerbated by his medication, making physical restrictions harder for him to take. She also said that because he was large for his age, she was concerned that his aggression could have consequences for others:

Respondent	Interview extract
<p>A_2</p> <p>Pre-school boy</p> <p>Parental concerns about aggression, but also sees it as normal</p>	<p>M: 'Unfortunately, at times, when he has too much [medication], it makes him very 'hyper', which he is anyway (laughs). He's so lively. Where's the rope?'</p> <p>....</p> <p>M: 'The only thing I worry about with him is because of his size, if he decides to punish a child, he'll send them flying across the room (laughs) because he's so big. I go to the school, and there are these little children down here (shows short height) and he's up here (shows tall height). So I say, 'No hitting, no fighting, no kicking!'</p> <p><i>Yet she saw his behaviour in general as very normal for a 4 year old:</i></p> <p>M: '.....he's just a typical, normal, four year old, trying everything that they can do, trying to push me to the limit.' (laughs).</p>

This respondent, in common with other parents whose children demonstrated externalising behaviour, did not feel fully in control of her child's behaviour. She felt that her child's age (and limited communication skills) meant that he was less able to express his feelings (and she less able to encourage him to express his feelings) in a calm manner.

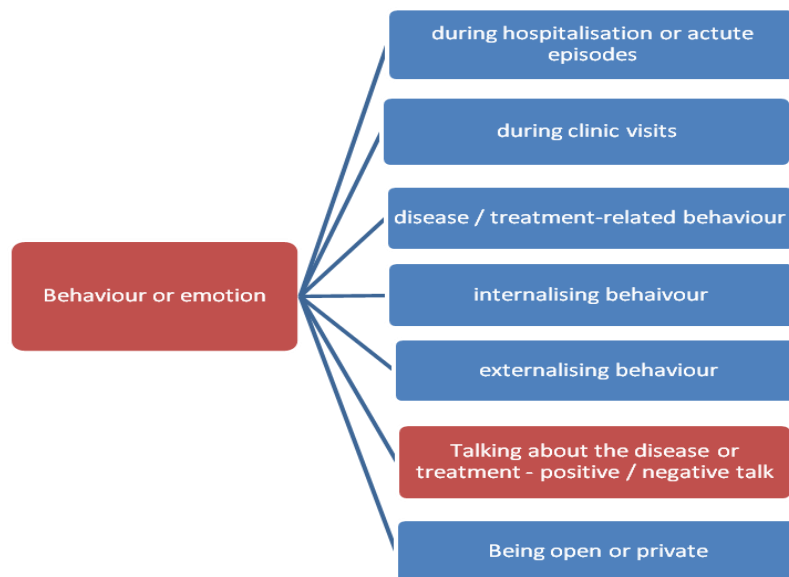
4.3.5.1. Summary of children's externalising behaviour and parent responses (Asthma Group)

This group of parents were sympathetic and understanding about their child's behaviour in general. In all cases, the asthma symptoms, the asthma history or treatment were felt by parents to contribute to the child's aggressive, argumentative or oppositional behaviour, in interaction with some individual child factor(s) (e.g. age, temperament).

Similarly to the parents whose children exhibited internalising behaviour, these parents often thought that their child could not fully control (and therefore change) their own behaviour. For example, argumentative behaviour was seen as normal for a teenager, but this behaviour was also attributed to insufficient oxygen getting to the child's brain (preceding an attack). If parents perceive that their child has little control over their own behaviour, this could make them feel less able to influence this behaviour personally.

4.3.6. Child Individuality of Response - Behaviour or Emotion: Talking about the disease or treatment - negative and positive talk (Asthma Group)

Parents frequently described how their child talked about their asthma or related symptoms. These feelings were coded as 'negative talk' or 'positive talk'. 'Negative talk' was not necessarily seen as problematic by parents, but rather considered that it was healthy for the child to verbally express his negative feelings. The subject matter of both 'negative' and 'positive' talk related to feelings about restrictions due to the illness (A_5, A_8), the symptoms or drug side effects themselves (A_4, A_7), the treatment (A_2), the illness in general (A_8, A_12) and future life (A_9, A_11). Further details about these examples may be found in Appendices 4.1 and 4.2.



The following two interview excerpts illustrate examples of ‘negative’ and ‘positive’ talk.

Child Individuality of Response - Behaviour or Emotion: Talking about the disease or treatment – ‘negative’ talk and ‘positive’ talk: Example of ‘negative talk’

Respondent	Interview extract
<p>A_8</p> <p>‘Negative talk’</p>	<p>M: ...A friend recently, you know from a long time, decided they were going to get a couple of cats. And this was the only house in Oxford that he could go and spend the night in. He didn’t do it incredibly often, but he did do it. But he did say to me, you know it went on for well over a week, him saying to me, ‘But I wouldn’t have done that, Mummy’. You know, so clearly, his disappointment, I think he keeps it low, but I think it is there, don’t you?</p> <p>F: Yeah, on the other hand, he’s a very cheerful, he’s naturally a very cheerful boy, and while he’s not unable to express negative feelings about something, his balance quickly reasserts itself, I think. And he has a sunny outlook on things.</p> <p>M: Yes, well I agree with you, but I do feel that it is down in there with him.</p> <p>F: Oh, I think he expresses it. I think he expresses it at the time, which I think is obviously very healthy.</p> <p>M: Yeah. Yes. Yes. But he has had to cope with quite a lot of disappointment. Some parties he can’t go to. Certain places he can’t go and do things. You know, so that’s difficult for him, and us actually. I find it difficult. (long pause, where parent becomes tearful).</p>

It is interesting to note these parents' differing reactions to their child's 'negative talk', with the mother perceiving it more negatively – believing that it reflected a more consistent, underlying degree of child upset at restrictions (and her associated personal distress), and the father perceiving this as a healthy way of coping; negative talk was a temporary and superficial state, as his son's 'natural cheerfulness' would help to counteract feelings of disappointment about restrictions. The mother seemed to focus on the basis of the negative talk, whereas the father focused on the benefits of the negative talk. It is interesting to consider whether one parent's more positive outlook on negative talk could help the other parent to be less distressed by this behaviour.

Child Individuality of Response - Behaviour or Emotion: Talking about the disease or treatment – 'negative' talk and 'positive' talk: Example of 'positive talk'

Respondent	Interview extract
<p>A_12</p> <p>'Positive talk'</p>	<p>M: And [child's name] doesn't worry. He was born with my disposition. He looks forward. After he's been poorly, he goes back to school and he says, 'I nearly died last week, but I'm back now and playing'. Whether that's his age, partly his makeup, he doesn't worry. He knows his asthma is serious. He knows he nearly died at Christmas, or could have died. But he doesn't drag it 'round with him, and it doesn't sort of bother him.....</p> <p>My daughter, because she is 11, and she obviously had to observe [child's name], she's frightened as well [as mother]. She's frightened that he could die of asthma, and you know if he wheezes, you can see her sort of go rigid. And you just say, 'Oh, it's OK; he's fine'. So in a way, you have to be extra brave for her, because you don't want her to sort of worry.</p>

As in other areas where parents describe child behaviour, this parent attributes the child's behaviour to the child's 'disposition' (reflective of her own), age and 'makeup', so would not feel responsible (other than through genetics!) for the child's positive talk. The parent may feel however that as her son is so 'brave', she should be positive as well (for the sake of the daughter), as implied in the latter part of the above excerpt.

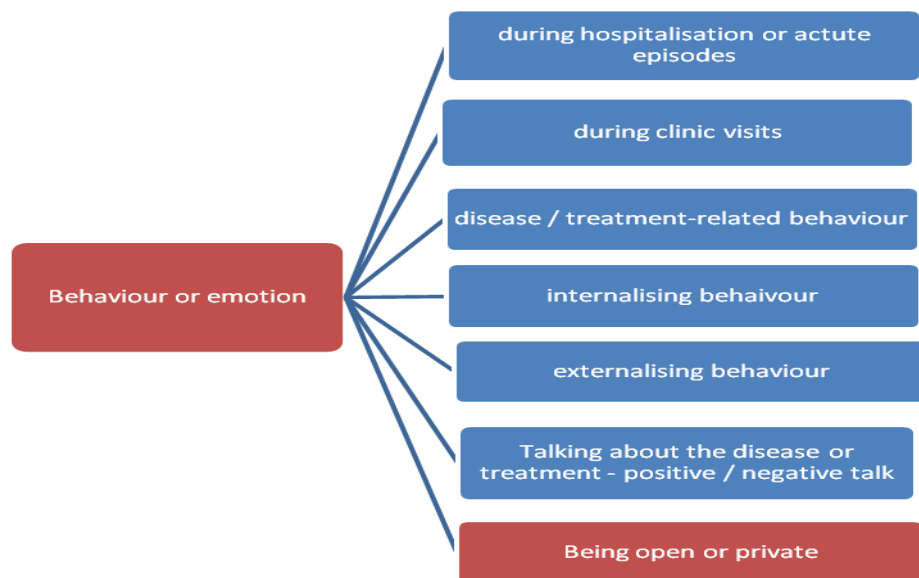
4.3.6.1. Summary of children's 'negative' and 'positive' talk and parent responses (Asthma Group)

More parents talked about their child's positive than negative talk, and often attributed the positive talk (or lack of negative talk) to their young age and / or naturally cheerful dispositions. In the more unusual examples of children's negative talk, parents tended to attribute the behaviour to the restrictions due to the disease and reflected how life would be different (better) without asthma. Parents generally thought that their child's outward 'talk'

genuinely reflected their feelings and acknowledged and sometimes encouraged this, for example by concurring that the child could get better, and outgrow his asthma.

4.3.7. Child Individuality of Response - Behaviour or Emotion: Being open or private about the disease or treatment (Asthma Group)

Five parents in this sample discussed their child’s feelings about being open or private about their asthma. A number of these parents discussed how their child didn’t like to tell (or show) others that he/she had asthma, asthma symptoms or treatment (A_5, A_6, A_8, A_9). Some parents felt this was motivated by the child’s wish to be ‘normal’ and like their friends and / or were denying their illness (A_5, A_6), or they didn’t want others to worry (A_8, A_9). In one case, a parent said their child did not try to hide their use of inhalers (A_9), and in another, the parent described how the child often deliberately took medication in front of friends (A_3) to gain attention. Further details about these examples may be found in Appendices 4.1 and 4.2.



Child Individuality of Response - Behaviour or Emotion: Being open or private about the disease or treatment: Example of child being open about the disease or treatment

Being ‘open’ about the illness was uncommonly highlighted by parents. It is possible that this is because for some children, there may be limited occasions when they need to carry out treatment-related activity near friends (i.e. taking inhalers). Therefore, being open or not perhaps was less salient for this group of parents. The following extract illustrates being open about treatment:

Respondent	Interview extract
A_9 Being open	M: And all his friends know he has asthma. He has inhalers at school, and the teachers all know. So it's not a sort of social issue. It's not something he feels he has to hide or anything.

Child Individuality of Response - Behaviour or Emotion: Being open or private about the disease or treatment: Example of child being private about the disease or treatment

In the following example which is more typical, the child doesn't like to tell his friends that he has asthma, and doesn't like telling his parent when he's feeling unwell.

Respondent	Interview extract
A_5 Being private about disease or treatment	<p><i>Being private with friends...</i></p> <p>M: ...And he doesn't want to be different. That's the other thing, so he doesn't like saying he's got asthma, because he feels like they [peers] will treat him differently and he doesn't want to be treated differently. He wants to be treated the same, or sometimes he can't because of it.</p> <p><i>Being private with parent....</i></p> <p>M: That's difficult, because also he doesn't like, sometimes when he's really bad, he doesn't like to tell me, so I'll find him in his room, struggling, and he'll say, 'I didn't like to tell you Mom', but you know, that means we've got to go to the hospital again, we've got to have an uproar again, and you know... He's got to go in for a while, and he says sometimes, 'It's not fair on everyone', which is not the way it should be really. It's difficult.</p>

4.3.7.1. Summary of children's being open or private about their asthma, and parent responses

Of the parents who discussed their child's emotions and behaviour concerning being open or private about their asthma, the majority reported their child's wish to be private. In common with the parent of A_5, other parents reported their child's reluctance to be open with peers about their asthma, because of wanting to be like other children (A_8, A_9) or behave as if they didn't have asthma (A_6, A_9). Interestingly, although the parent of A_9 (aged 10) said her child's friends and teachers knew he used inhalers, he did not take them with him when he went out with friends. This parent felt this was because her son considered that taking

inhalers with him was an admission that he wasn't like his friends and could have an asthma attack, which the parent believed her son didn't want to consider. In contrast, the parent of A_3 reported that her teenage daughter deliberately took inhalers in front of friends 'for effect', as a way of drawing attention to herself. These differences may be related to the differences in the social skills and social confidence of the individual children.

However, in all of these cases, whether the child was open or private, the parent expressed some concern about the child's behaviour. In the case of A_3, the concern was that the child's excessive use of inhalers in front of friends was leading to an overdose of drugs and was not socially appropriate (attention-seeking). In cases where the child wanted to be 'private', parents felt that such behaviour could create health risks, although they were sympathetic to the child's motivation to be treated normally and / or for adults not to worry about their health.

4.4 CHILD INDIVIDUALITY OF RESPONSE - BEHAVIOUR OR EMOTION: DIABETES GROUP

4.4.1. Child Individuality of Response - Behaviour or Emotion: Behaviour or emotions relating to hospitalisation or acute episodes (Diabetes Group)

The children in this group, unlike the asthmatic group, were rarely hospitalised, except at diagnosis. Hence, fewer participants discussed child behaviour in hospital situations (except at clinic). In cases where children were hospitalised following diagnosis, it was either because they had been non-compliant with treatment regimes or had acquired a temporary illness which made diabetes control more difficult to manage at home. The following participants described their child's behaviour as an in-patient in hospital: D_3, D_12 and D_13 (at diagnosis), and D_5, D_7 and D_15 (at subsequent admissions). It is possible that other parents did not describe their child's behaviour at diagnosis when in hospital, if it was a long time previously or their child had been very young.

Children's behaviour during acute episodes that did not just describe clear physical symptoms (e.g. light-headedness) and did not involve a hospital admission was reported by parents in four interviews (D_4, D_7 D_9 and D_10). These acute episodes were due to either hypoglycaemic (low blood sugar) or hyperglycaemic (high blood sugar) attacks. Symptoms of mild hypoglycaemia are commonly and frequently experienced by children with relatively good illness control, although severe hypoglycaemia could lead to a hospital admission. In contrast, symptoms of hyperglycaemia might not be evident unless high blood sugars are

fairly sustained, and are not expected in children with good diabetes control. A symptom of either very high or very low blood sugars is behavioural changes such as aggression, irritability or uncooperativeness. As discussed in section 4.4.2.1, this sometimes made it difficult for parents to distinguish between symptomatic behavioural changes and how the child would have been without low or high blood sugar levels.

The following child behaviours were reported by parents during hospitalisation (at diagnosis):

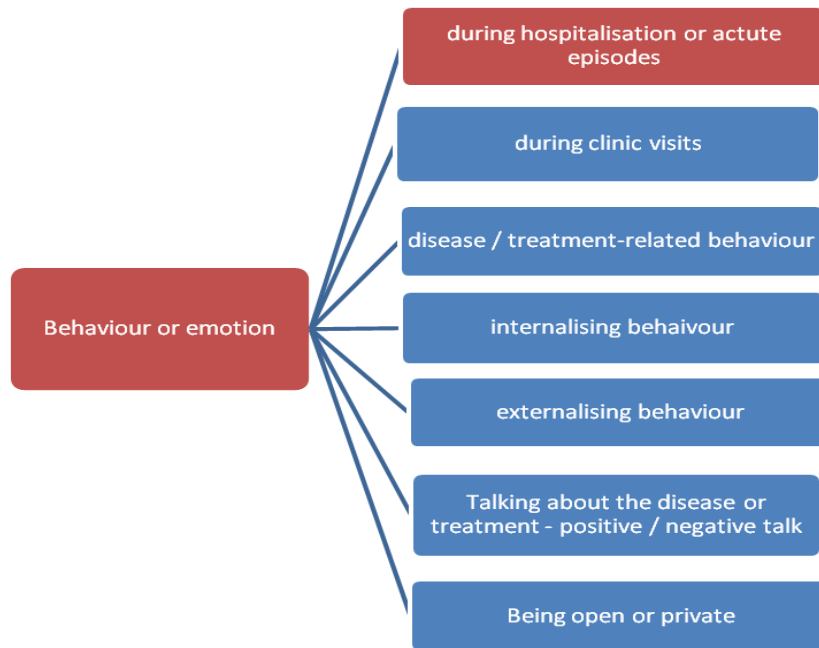
- a) Being stoic / not minding having injections (D_12)
- b) Distressed about having diabetes (D_3, D_13) and invasion of privacy (D_3)

The following child behaviours were reported by parents during hospitalisation (post-diagnosis):

- a) Food refusal (D_15)
- b) Dislike of being in hospital (D_7)
- c) Frightened / traumatic (D_3, D_5)

The following child behaviours were reported during acute episodes:

- a) 'Difficult' behaviour, uncooperative during hypo (D_2, D_4, D_7, D_10)
- b) Worried and frightened after hypo; not wanting to be left alone (D_9)



Child Individuality of Response - Behaviour or Emotion: Child behaviour or emotions relating to hospitalisation or acute episodes: Example – Distress during hospitalisation

Unlike the children in the asthma group who were mostly diagnosed as toddlers, the diabetic children were diagnosed at any age, including during adolescence. Furthermore, the diagnosis of asthma tends to be based on the gradual appearance of symptoms over months and possibly years, with the diagnosis often being suspected by parents before being confirmed by doctors. On the other hand, the diagnosis of diabetes is normally sudden and unexpected. This could contribute to the distress children expressed in hospital at the time of diagnosis.

Also, the two parents who described their children as having been distressed in hospital were diagnosed during adolescence. It is possible that these children were more aware, in view of their more advanced cognition, of the implications of the diagnosis. The interview extract of the parent of D_3, whose child had two hospital admissions since diagnosis is given below:

Respondent	Interview extract
<p>D_3</p> <p>Adolescent girl</p> <p>Distress during hospitalisation</p>	<p>M: But again, it all comes back to the former hospital visit, which comes back to the original hospital visit, and I suppose she was very tearful, very very tearful. She said how much she hated her diabetes and she had to tell them she had her period, and she hates that because you know, that's me and that's private, and I don't want everyone to know about it. She had to tell them. It's those little invasions that, it's quite hard on a teenager. And you know, she had the magic cream on her in case they needed a blood test. So again, that's the thing that really freaks her out. When we have our annual review here, and the staff here are wonderful because they know how much it upsets her, and they really really deal with that fantastically well. But you know, she was all gunged up ready for it, and in the event it didn't happen. But it's just a bit of a stressful situation.</p>

It was evident in the two examples where the child showed distress at being in hospital that the parent felt stressed. Having had distressing experiences during blood tests in the past (taken from a major vein, rather than the finger prick blood sugar tests) contributed to this girl's distress, as did the need to reveal private information.

Child Individuality of Response - Behaviour or Emotion: Child behaviour or emotions relating to hospitalisation or acute episodes: Example – ‘Difficult’ behaviour / uncooperative during hypo

The following example of ‘difficult’ behaviour was relatively commonly reported by parents, in association with hypoglycaemic attacks:

Respondent	Interview extract
<p>D_7</p> <p>‘Difficult’ behaviour / uncooperative during hypo</p>	<p><i>During hypoglycaemic attacks:</i></p> <p>M: [Child's brother's] panics. He doesn't know what to do. He can't deal with it. 'Cause it was one morning half past 3, I heard [child's brother] shout, '[child's name], what are you doing sat up in bed'? And he was low then. So, 'cause they share a room, if I'm trying to get glucose tablets or something into [child's name], he gets angry, and he says, 'For God's sake [child's name], just eat the tablet (or eat the sweet)' sort of thing - he gets angry, [brother's name] does.</p> <p>I: But he knows he needs to eat something?</p> <p>M: Yeah, he knows - that's what I'm saying. Because diabetics don't do as they're told when they're going into a hypo. My mother was the same. My husband was the same. And [child's name] will - although they don't obviously know what they're doing, he seems to know at that point - I'm trying to get something in his mouth and he's burying his head in the pillow.</p>

The above respondent and other parents who described hypoglycaemic attacks know that diabetics are often uncooperative when going into a 'hypo'. However, this respondent seemed to imply that she believed her child was aware that he should eat something but refused to do so. This may have contributed to her feelings of frustration and stress expressed elsewhere in the interview about her son's externalising behaviour.

4.4.1.1. Summary of children's behaviour or emotions relating to hospitalisation or acute episodes and parent responses (Diabetes Group)

Most of the children in this sample had not been hospitalised, except during diagnosis. In many cases, diagnosis had occurred when the child was very young. This could account for why parents did not often discuss their child's behaviour during hospitalisation. When the child was diagnosed as an adolescent, parents were more likely to report that their child was distressed or frightened in hospital. This could be related to the adolescent's greater understanding and appreciation of the illness and its consequences. Parents found their child's distress to be stressful for them, particularly when procedures were carried out that they knew, from previous negative experience, would lead their child to feel anxious.

Behaviour reported during acute episodes mostly related to when the child had abnormal blood sugar readings. The most frequently-reported behaviour was uncooperativeness during hypoglycaemic attacks. Whilst parents recognised that abnormal blood sugar readings could induce such behaviour, it was clear that in some cases the parent was uncertain how much control the child personally had over their behaviour. This was frustrating for the parent, as it was important to gain cooperation of the child in order to administer treatment to resolve the hypoglycaemia.

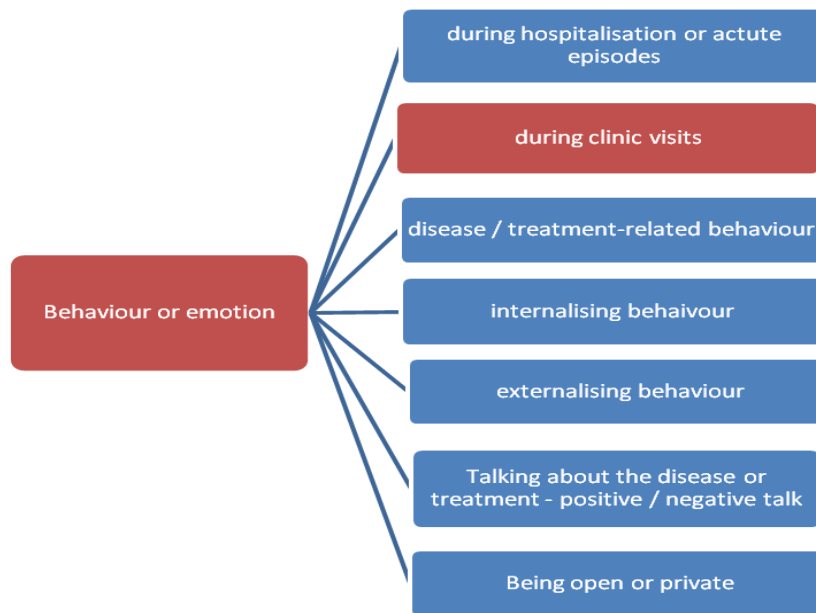
4.4.2. Child Individuality of Response - Behaviour or Emotion: Child behaviour or emotions during clinic visits (Diabetes Group)

The children in the diabetes group were expected to attend clinic every 3 months, with an annual review ('MOT'). The clinic visits could involve growth measurements and taking blood for HbA1c, which is a test of glycosylated haemoglobin, or the amount of glucose taken up by red blood cells. It is a measure of compliance with treatment. The parent and child normally discussed their progress with the doctor or nurse, but occasionally adolescents came to clinic on their own.

Respondents reported the following types of child behaviour at clinic:

- a) Usually enjoys clinic, finds it interesting and likes to play (D_4, D_5)
- b) Sometimes nervous or anxious at clinic due to blood test (D_1, D_5)
- c) Formerly didn't like going to clinic because they felt they were being 'told off', but doesn't mind now (D_11)
- d) Doesn't listen or take on board information at clinic, uncommunicative (D_8, D_11)
- e) Hates attending and talking to people at clinic – walks out (D_7)

As the type of behaviour identified in a, c and d above were also reported by respondents from the asthma group, examples from b and e have been selected as illustrations.



Child Individuality of Response - Behaviour or Emotion: Child behaviour or emotions during clinic visits - Example of showing upset

The respondent below discussed that her child's response to having blood drawn at clinic for the HbA1c test for 'MOTs' (annual review). This child has also demonstrated anxiety about injections, although this is improving as he gets older.

Respondent	Interview Extract
<p>D_1</p> <p>School aged boy</p> <p>Upset at having blood taken</p>	<p>I: So he doesn't really get upset at all on hospital admissions [not for diabetes] as such.</p> <p>M: No, no, he's....</p> <p>I: It just sounds like it's just when he goes for the MOTs.</p> <p>M: MOT, no we don't do the MOT. That's an issue.</p> <p>I: How do you usually react when he sort of gets upset.</p> <p>M: Upset. It's horrible. You're upset that you can't show him that you're upset. As soon as the magic cream comes out, that's it. He freaks. He absolutely, he has such a fear of needles, it's freaky. It's horrible. And he knows when it's his MOT team, that they're going to do it. But the play nurse there is brilliant. And she will, she talks to him, and she sits with him, and she blah blah blah.... And the last time he had it done, he didn't even know that they'd done it. So that was fantastic.</p> <p>I: That's good, that's good. Do you do anything that you feel is helpful in those circumstances?</p> <p>M: No. (laughs)</p> <p>I: I mean do you act in a particular way or just withdraw?</p> <p>M: 'You just stay here, I'm just going to leave you!' (laughs) No, because they're the specialists - I'm not the specialist. They are the specialists and that's a bit like trying to tell a chef how to boil an egg isn't it? (laughs)</p> <p>I: I don't know, children often want their Mums, don't they.</p> <p>M: He's quite big for me to hold his hand... just touching. As long as he knows I'm there that's fine.</p> <p>I: He's happier for you to...</p> <p>M: I couldn't put him in the room and say, 'Right. See you in 5 minutes'. (laughs) That just doesn't happen. But as long as I'm there and he knows I'm there, then that's...</p> <p>I: So have you always done that or have sometimes you tried other..</p> <p>M: Oh no well we've tried this sitting in the room on my lap, that.-I mean at the beginning he was sat on my lap, with one arm 'round here and one arm 'round there and him there and the legs were going and everything was going and there'd be 3 or 4 nurses in there all trying to sort of do it. That just doesn't... he's too big to do that to him now. When he was little you could. So now we have to employ different tactics.</p> <p>I: Right, so you feel it's improving anyway.</p> <p>M: Oh yes.</p>

The other child who expressed distress at his blood test during clinic was D_5; parents said he is nervous about having blood tests but proud when it is finished and he knows he has coped alright. Parents of both children did not exhibit distress, were supportive during these experiences, and were pleased that as their child was getting older, they were coping better. Both of these children were young school-aged boys (aged 9 and 10). This type of behaviour was not reported by parents of older children.

Child Individuality of Response - Behaviour or Emotion: Child behaviour or emotions during clinic visits – dislikes clinic and walks out

The following respondent reported the only example of their child consistently disliking all aspects of going to clinic appointments:

Respondent	Interview Extract
<p>D_7</p> <p>Adolescent boy</p> <p>Disliking clinic walking out /</p>	<p>I: So he doesn't like going to the hospital at all?</p> <p>M: No, no, once he just walked out. He hates talking to people. He couldn't sit and do this. He don't like it when the doctors talk to him. He wants me to talk for him. I mean he just doesn't like doing any of that. It wasn't too bad last time. I actually got called in and he went in on his own. And then she called me in after. So, I thought, 'Well, that was a good sign'. The fact that he did sort of speak to her on his own. No, there's been times when he's got up and walked out - walked out of the hospital.</p> <p>I: Before his appointment, or?</p> <p>M: No, we've been in there talking to the doctor, and he's just got up and walked out. So, I think a lot of it, as I said, is that he's got a lot of anger, due to his Dad dying as well. I don't know. I can't put it all on that, but I mean at school he's had anger management, and sometimes he's throwing a tantrum at school. So, I mean I can't blame it all on this, but that certainly doesn't help.</p> <p>.....</p> <p>I: So when he knows there's a clinic appointment approaching...?</p> <p>M: 'Do we have to go?' (laughs). Yeah. Especially the May one. Because he has to do urine samples for three mornings, and although he does do them, but I have to make sure the bottle's out for the first wee he does, and 'Don't forget to do it'. But also he doesn't like it because although he has to do his blood, we have to fill up the other little tube as well, the Hb you know.</p> <p>I: The HbA1c.</p> <p>M: Yeah. So yeah, and then the fact - it's the trip up there. He hates going up there. It's two bus rides away, 'cause I don't drive. So it's time consuming and he can't be bothered with it.</p>

This parent described her son's behaviour and emotions in relation to clinic attendance in the context of other difficulties generally with controlling his anger and his parent described both externalising and internalising behaviour in other settings. Thus, this seems to be related to more general emotional and behavioural problems, rather than specifically being related to the clinic per se.

4.4.1.1. Summary of children's behaviour or emotions during clinic visits and parent responses (Diabetes Group)

A couple of parents described how their child liked or took an interest in clinic visits (D_4, D_5); some children didn't mind or liked coming to clinic, but disliked the blood tests (D_1, D_3, D_5). Parents expressed satisfaction that their child showed an interest in their health and were learning to cope well with the blood tests. Other parents said their child was not very communicative at clinic. These were adolescents (D_8, D_11), and parents attributed this behaviour to this stage of development, and 'stropy moods' (D_8). The parent of D_11 felt her son's behaviour was improving, as he was feeling better about himself as he was growing more in size (being small for his age). A further parent of an adolescent (D_9) said her daughter used to not like to go to clinic because she felt she was being 'told off', but now found it 'OK'. One adolescent (D_7) exhibited angry and uncommunicative behaviour at clinic and disliked all aspects of the experience.

The data from those parents who discussed this aspect of their child's experience suggested that younger children tended to enjoy clinic more, except the blood tests. They were interested in their health and enjoyed playing with the toys. However, the adolescents seemed to view the clinic experience more negatively. This seems not to be connected specifically with the clinic, but was an extension of more general behaviour exhibited outside the clinic experience. Although not mentioned by any parents in the context of the clinic experience, one parent reported how her adolescent daughter generally worried about having high blood sugar levels because of the long term complications (D_3); at the clinic when blood is taken for HbA1c, the families know the result before they leave. It is possible that some adolescents, who are more aware of the implications of sustained high blood sugar levels, may approach clinic appointments with some worry.

4.4.3. Child Individuality of Response - Behaviour or Emotion: Disease / treatment-related behaviours

This section reports parents' descriptions of their child's treatment-related behaviour. This excludes behaviour directly related to administration of injections and testing blood sugar readings to control and manage the illness, which is discussed in Chapter 5. However, it includes related behaviour such as secretive eating or food refusal, emotions and behaviour relating to taking responsibility, and other general feelings and behaviour about the treatment or results.

Most treatment-related behaviours reported by parents related to issues concerning feelings and behaviour about taking responsibility for their illness. Eating behaviours were commonly reported in this context. Explanations for the child's less responsible behaviour could be attributed to a number of reasons, some of which the parents proposed. These included wanting to be normal, not wanting to think about or focus on the illness, or not accepting the illness. Other areas discussed by parents included the child's dislike of being 'nagged' to carry out treatment, the child's 'using' the illness and monitoring their illness state. These are summarised below, and reported in more detail in Appendices 4.3 and 4.4.

Taking responsibility:

Child is responsible, tells others when unwell (D_5, D_6)

Assertive when adults give incorrect advice (D_12)

Food-related behaviours:

Finds it difficult not to have sweets, but follows advice (D_3, D_6)

Never fussed about restrictions of sweets or food issues (D_9, D_12)

Not taking responsibility / not accepting illness / being normal/ minimising focus on illness:

Occasionally won't tell others when unwell when with strangers, as this will stop her playing (D_2)

Lying in bed in the morning when they should be getting up to eat and to start treatment (D_7, D_13)

Food-related behaviours:

Food refusal (D_2, D_4, D_6, D_11, D_14, D_15)

Doesn't take breakfast bar in her bag in the morning (D_14)

Hiding food or eating sweets secretly / making a fuss when can't have certain food (D_8, D_15)

Feelings about reminders concerning treatment:

Doesn't like parent to offer advice or 'nag' (D_7, D_9, D_11)

Other general feelings or behaviour relating to treatment or treatment results:

Using illness:

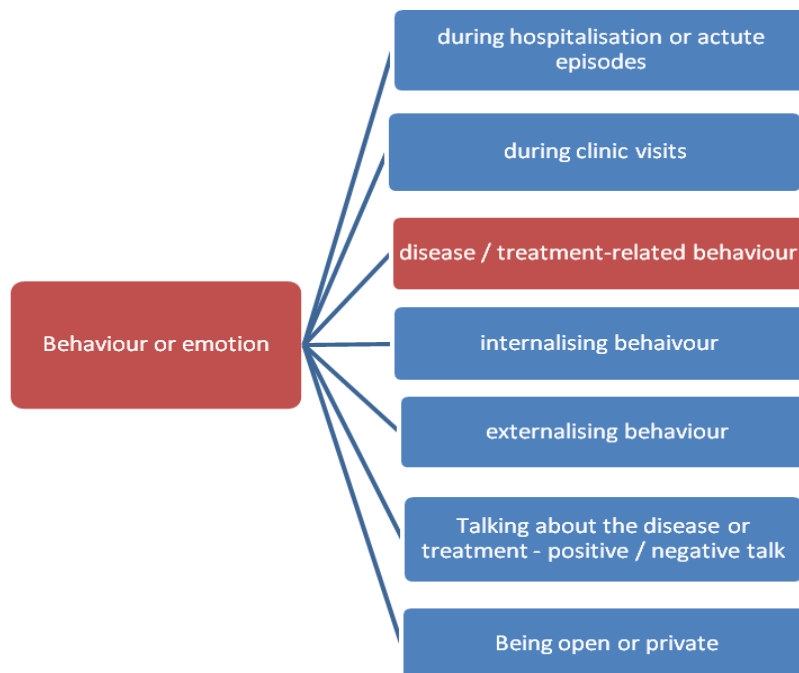
Attention-seeking behaviour - incorrectly claiming unable to manage in order to increase parental attention (D_14)

Pretends to have symptoms to avoid doing something (D_14)

Monitoring illness state

Feels stressed when observing blood test results, and not being able to lose weight (D_3)

Gets excited when blood sugar levels are low (D_13)



Child Individuality of Response - Behaviour or Emotion: Disease / treatment-related behaviours: Example – taking and not taking responsibility in food-related issues (Diabetes Group)

The following extract illustrates food-related behaviours detrimental to health that were commonly reported in this sample:

Respondent	Interview extract
<p>D_8</p> <p>Hiding food</p>	<p>F: ...We would much rather she [daughter] said, 'I've sat down and I've eaten a Christmas pudding', than not tell us. I'd be angry that she'd done it, but we can still put it right. We can negate the effects of it. But if you don't tell us, then we can't and that's the most worrying. So it's an honesty issue - and the problem is, because you've become a bit officious, because you're concerned, the honesty isn't so up front. You know?</p> <p>M: We've been there. I've found...chocolate wrappers in places you'd never think you'd find chocolate wrappers. That's why I'd start serving up chocolate with every meal 'cause I thought that might help.</p> <p>F: You know, if you want it that bad, have it, but we can then put it right.</p> <p>I: But that's different now, you were saying.</p> <p>F and M: Yeah.</p> <p>F: I mean it still happens occasionally, but it is a lot better. A lot better. Yeah, there's going to be small transgressions, you can't stop that.</p>

These parents believed that their child (even though an adolescent) might not be able to control urges to have sweets / chocolates. The mother tried to bring some control to this situation by regulating the availability of chocolate (at the end of meals), and parents encouraged the child to be open about what they perceived to be inevitable transgressions by not 'being officious'. The 'meaning' they placed on this behaviour was therefore that the child's behaviour was due to a lack of self-control, perhaps relating to the child's immaturity.

A different reason was offered by the other parent who reported eating sweet things without the parent knowing (D_15). This parent expressed frustration at the behaviour ('tearing her hair out') and regarded this behaviour as consistent with other challenging behaviour and 'emotional struggles' that her son exhibited, which was related to his wish to be 'normal'.

Thus, the way that parents interpret such behaviour (e.g. inability to control urges due to immaturity, or reflective of emotional disturbance because of diabetes) influenced how

seriously they perceived the behaviour to be – i.e. something that ‘normal’ children struggle with, so the behaviour just needs managing, or reflective of some more deeply-seated problem connected with poor adjustment to having diabetes, with the implication being that a deeper level of intervention would be needed, which the parent on her own could not offer. Data later in this parent’s interview bears out this hypothesis, and is reflective in her comment about ‘tearing her hair out’ over this behaviour.

4.4.3.1. Summary of disease / treatment-related behaviours and parent responses (Diabetes Group)

Most of the child behaviours and emotions reported in this section related to whether or not children seemed to take responsibility, mostly in the area of food. Food refusal or hiding food and secretly eating sweets were reported. Parents offered different explanations, including that their child hadn’t accepted or were denying the illness (D_11, D_14), and / or were using the illness to manipulate others (D_14 and father of D_4), that they were just trying to be normal and also to exert control (D_15), or were not mature enough to control urges for sweets, particularly as it is difficult to resist urges for things that are not allowed (D_8).

Parents had different emotional and behavioural responses to these behaviours. One mother felt personally rejected when her daughter refused food (D_14), and parents expressed frustration (D_14, D_15), firmness (D_6 and father of D_4), or encouraged openness (D_8). The parents of D_4 disagreed about how to handle food refusal, with the father insisting the child should eat what was offered and the mother wanting to offer multiple food choices (D_4).

Some parents reported that food issues were not (or rarely) problematic, and that their child had behaved responsibly (D_3, D_6, D_9, D_12). Reasons respondents offered were that their child was mature and also were treated more like an adult within the family (D_12), that they liked ‘healthy food’ (D_9), had supportive friends (D_3) and that the mother had instilled a sense of responsibility by impressing on the child that it would be her own fault if her blood sugars went ‘low’ – i.e. that she had personal control over her blood sugar levels (D_6).

A number of parents indicated that their child disliked being ‘nagged’ to look after their health; however, they didn’t always feel that their child could be trusted to manage the illness and treatment appropriately. These children were nearly all adolescents. This resulted in

some degree of parental worry, as on one hand they recognised that the child needed to start taking responsibility, but on the other hand they were not confident of their motivation or ability to do so.

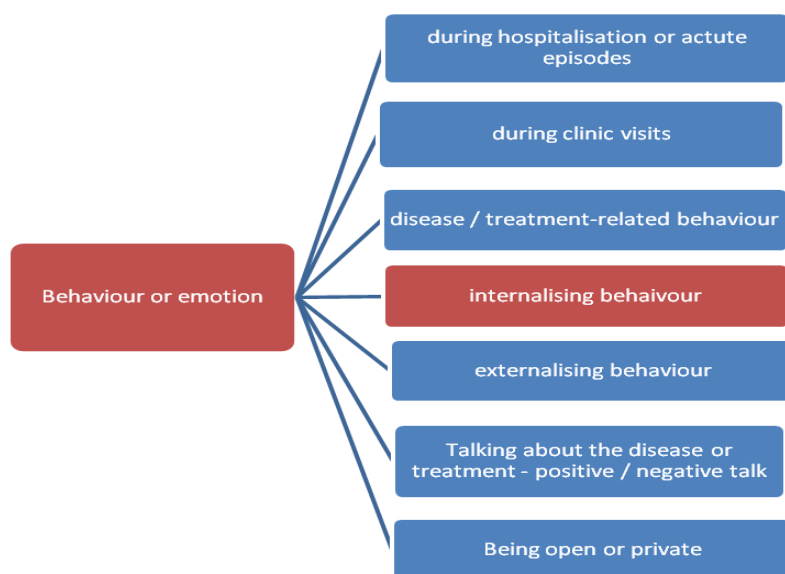
4.4.4. Child Individuality of Response - Behaviour or Emotion: Internalising behaviour (non-hospital) (Diabetes Group)

The majority of parents in this sample described their child's internalising behaviour (such as being withdrawn and feeling 'down' or 'fed up'). As was the case with the Asthma Group, many parents discussed what they believed to be the origin of the child's feelings and/or behaviour. Explanations were sometimes based on their child's attributes (such as their temperament, personal characteristics, habits or developmental age), and occasionally social experiences in interaction with the disease. Most commonly, causes were attributed to the disease or treatment, or an interaction between individual and these disease-specific factors. These parents frequently expressed a sense of helplessness and / or distress about their child's internalising behaviour.

Overall, respondents in ten interviews reported internalising behaviour, D_3, D_5, D_6, D_7, D_9, D_10, D_11, D_12, D_13 and D_15. The most common group of behaviours reported by parents was low mood or depression; these feelings varied in frequency, severity and length of occurrences. Parents reported that their child had depression, unhappiness, felt 'fed up' or expressed a low mood (sometimes occasionally, sometimes frequently). Some form of this behaviour was reported by eight respondents (D_1, D_3, D_5, D_6, D_8, D_11, D_12 and D_15). Three of these children seemed to experience (or have previously experienced) more significant and regularly-occurring feelings of low mood or depression (particularly D_3, D_11 and D_15).

Withdrawn or socially avoidant behaviours were reported by some other parents (specifically parents of D_5 and D_10). A couple of parents reported physically internalising behaviours such as nightmares (D_6) or headaches and tummy aches, associated with school avoidance (D_12). Appendices 4.3 and 4.4 include further information about these examples.

The two examples selected as illustrative of internalising problems reported by parents were of D_11, who described her child's feelings of depression (D_11) and D_13, the parents of a child who was often withdrawn.



Child Individuality of Response - Behaviour or Emotion: Internalising behaviour (non-hospital): Example – depressed feelings

In the following example (D_15), the parent reported a range of behaviours of her child that caused her concern, including her child’s depressed feelings and expressions of low self-worth.

Respondent	Interview extract
<p>D_15</p> <p>Depressed feelings</p>	<p>M: He feels he’s different, he feels he’s not good enough, that he’ll never be able to do this, never be able to do that, so it’s a real knock on his confidence. And he struggles with, like, because I do his injections and stuff, with being the baby and the boy. You know, he’s stuck between growing up and not growing up. So it’s difficult. So he came out with lots of issues that he refused to eat, anger outbursts, tantrums, really silly behaviour.</p> <p>I: So this was quite a while ago now?</p> <p>M: Only last year. And he still struggles with it. And you know, at the moment, I’m getting help to help deal with these certain situations, because he can’t seem to express it. It comes out in anger and physical. So I’m now seeking help to learn how to sort of diffuse him. But it always boils down to ‘why have I got this?’, ‘why was it me?’ ‘have I been bad?’, and I needed some support about what do I say. What do I say to this little boy, ‘Mom, why have I got it?’ ‘What does this mean?’ ‘Have I been a bad person?’ ‘Am I going to die?’ I mean, he went through a stage of saying, ‘I wish I was dead.’</p> <p>I: Oh dear.</p> <p>M: And to hear that from a little 7 year old boy, it broke my heart.</p>

As in the above example, some parents felt that their child’s depressed feelings stemmed from the child’s perception of being ‘different’ and not wanting to accept the illness, or hating the

illness. For example, respondent D_3 felt her child's depressed feelings (feeling 'bitterly upset' / 'beside herself') related to the difficulty she experienced in trying to be slim like her friends (because she couldn't lose weight and still control her illness). Some parents attributed the child's depressed feelings to the excessive burden of stressors that were additional to diabetes, for example in the case of D_7, whose parent felt that the child's father's death contributed to his depression, another because the child's father had developed a mental illness (D_11), and in a further case because of inconsistent support by teachers at school (D_12). A few parents felt that the child's moody behaviour was also partly related to being an adolescent (D_3, D_9, D_10 and D_11) and, related to this, in the case of D_3, a feeling of not being able to be as independent as she'd like to be because of the illness.

Mothers generally found it difficult and worrying to watch their child 'struggling', particularly in cases, for example D_10 and D_11, where the child denied they needed help. One parent (D_3) referred to her child's personal characteristics as contributing to the difficulty; she felt that being an independent child made the increased dependency due to the illness more difficult to accept.

Child Individuality of Response - Behaviour or Emotion: Internalising behaviour (non-hospital): Example – social withdrawal

Social withdrawal was less commonly reported in this sample, with one father saying his child was naturally 'a loner' (D_5) and one parent saying that the child communicated less with parents (D_10), which they thought could be a 'teenage thing' or due to having 'hypo' symptoms. School refusal / feigning illness to avoid school was possibly an example of social withdrawal in two cases (D_12 and D_13), with the latter parents suggesting this was due to inconsistency with teachers at school, which made their daughter stressed. In the following example (D_13), parents reported the child's reluctance to go out, and also problems with avoiding school.

Respondent	Interview Extract
<p>D_13</p> <p>Social withdrawal</p>	<p>F: Psychologically, she tends to be cautious, doesn't she?</p> <p>M: She's become a wee bit of a home girl, where before would go here, there and everywhere.</p> <p>F: She won't stray too far now.</p>

	<p>M: I think she's scared to, just in case she has a hypo or forgets anything.</p> <p>I: Does she tell you that?</p> <p>F: No, it's the impression we get, because we say, 'Why don't you go out to play?' 'No, don't want to.'</p> <p>M: I found it, you know, she sort of went like it before she was diagnosed, wasn't she, and I think it scared her.</p>
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The above respondents also reported how their daughter often wanted to come home from school, saying that she was ill (when they believed she wasn't). They felt this was because of her anxiety at starting a new school, in combination with the diabetes. It was evident that these parents were worried about their daughter's social withdrawal and school problems, but felt they had not been able to talk to anyone about their concerns. The parents seemed to feel that this behaviour was caused by anxiety, but also the father wondered whether the parents were partly to blame for being too overprotective. This child was the most recently diagnosed of the whole sample (just one year), and it is possible that the rapidity of lifestyle changes required might have increased the degree of anxious behaviour.

4.4.4.1. Summary of children's internalising behaviour and parent responses (Diabetes Group)

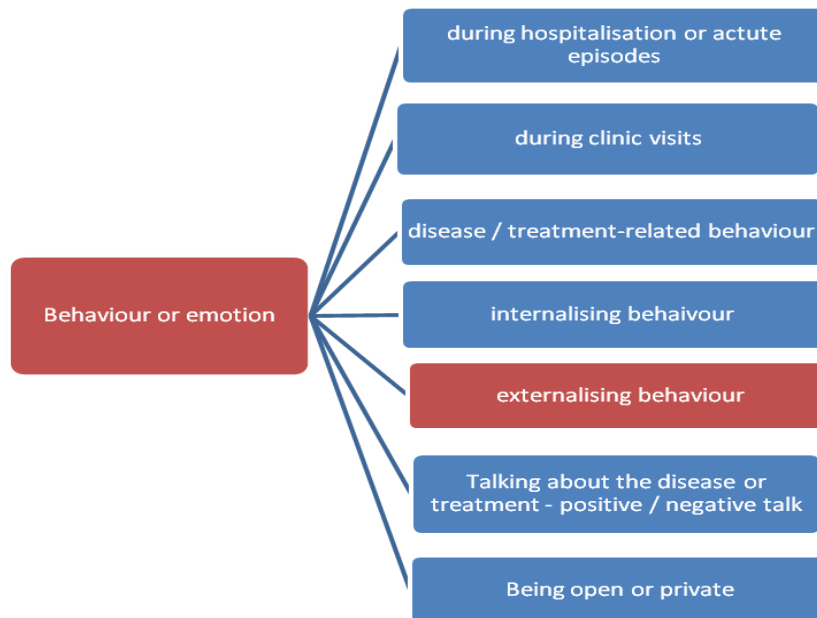
The form of internalising behaviour most frequently reported by parents was low mood / depressed feelings or feeling 'fed up' or 'hating diabetes'. For the majority of children, these feelings were not persistent or extreme, for example with parents describing occasional 'I hate diabetes' days. However, for a few parents, the low mood / depressed feelings were of significant concern and led them to feel helpless, particularly when their child refused help or they felt unsupported. In most cases, parents felt that their child's feelings related directly to the illness, particularly its constraints and unpleasant treatment, sometimes in combination with other stressors within the family or school life, and sometimes related to age (being a teenager).

Less commonly reported internalising behaviours included social withdrawal, manifested as not wishing to go out to play or feigning illness (or expressing internalising symptoms like 'tummy ache' and headache), leading to school avoidance. There was one example of possible internalising symptoms of nightmares, although these also could have been related to hypos. In these cases, parents attributed the child's behaviour to anxiety, either about the possibility of experiencing unexpected symptoms when unsupervised, or connected with

school-related anxieties (possibly also linked to the diabetes). It is possible that social withdrawal is more common early in the illness history, before the child has gained confidence in self-management and is more able to predict when and how symptoms may occur.

4.4.5. Child Individuality of Response - Behaviour or Emotion: Externalising behaviour (non-hospital) (Diabetes Group)

Ten respondents discussed their child's externalising behaviour (D_2, D_3, D_4, D_7, D_8, D_10, D_11, D_13, D_14 and D_15). In many of these cases, this took the form of anger (D_3, D_7, D_11, D_14, D_15,) and / or stubbornness or argumentativeness / 'stoppiness' (D_2, D_7, D_8, D_10, D_13, D_14) or irritability, with bad moods (D_4). It is possible that some of this behaviour could be attributed to fluctuations in blood glucose, as either high or low blood glucose can affect mood. Indeed, some parents referred to their child sometimes being in a 'hypo mood'. However, they normally also refer to age-related or personality-related characteristics, or personal life experiences (related or unrelated to the disease) to explain their child's behaviour. For some children, the angry or argumentative behaviour was frequent and persistent, whereas for other children it was sporadic and infrequent.



Child Individuality of Response - Behaviour or Emotion: Externalising behaviour (non-hospital): Example – expressed anger

The interview extract below was from the interview of a mother and father (D_14) who reported both angry and stubborn child behaviour, which were also reported by a number of other respondents in the sample.

Respondent	Interview Extract
<p>D_14</p> <p>Expressed anger</p>	<p>M: You know, because when they get stroppy in a hypo mood, I mean it's the doors are slammed, the windows are slammed and 'I hate you!' and when the door goes and she goes off, I mean I hadn't told you this [to father]. I was going to tell you this last night - she was having a screaming fit outside. Well, if she wants to go outside then I'm afraid now I just let her scream. And somebody came along from the village 'cause they thought she'd fallen off the horse! (laughs)</p> <p>I: But she probably screams less now that you don't respond to it quite so much, maybe?</p> <p>M: We just ignore it, but she just goes outside and screams. So if she wants to go outside and scream, that's fine.</p> <p>F: Rips up flowers in the summertime.</p> <p>M: Just go outside and scream.</p> <p>I: She feels angry?</p> <p>F: Oh Christ. You've got no idea. I've got no idea.</p> <p>M: I mean the funniest thing was, we were mending a fence and she was in a strop. She gets - whenever her sugars are up and down, she gets very moody anyway. Anyway, her and her brother, they were fighting and arguing like they do. Anyway, they were rolling 'round the field and they were biting and fighting and anyway, [name] says, 'Oh, you've got to stop them!' And I said, 'No, they'll be alright.' (laughs) And I said, 'As long as there's no blood or bones, you just....you know'. And they just got up and they were perfectly alright. But she does get very - it's the mood - the mood with it. Because she says some very hurtful things - 'I hate you!' You know, 'You're horrible!' And you say, 'Yeah, fine, I know'.</p> <p>F: But, as I say, with all of it.....</p> <p>M: I think everybody goes through this.</p> <p>..... [elsewhere in the interview...]...</p> <p>I: Yes, sometimes when they're hypo, they behave rather oddly, don't they?</p>

	<p>M: Oh yes.</p> <p>F: Oh yes.</p> <p>I: Was that part of it, perhaps, was it, why she was being so stubborn, slightly? [refusing food]</p> <p>F: She's stubborn anyway.</p> <p>M: She's a very stubborn girl.</p>
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The responses of parents to this kind of behaviour varied, and this partly depended on what they considered the cause to be. For example, although respondents D_14 (above) partly accounted for their child's behaviour as being due to high or low blood sugars, they also said she was a 'stubborn girl'. Additionally, this child frequently refused to eat what her mother wanted her to (i.e. more vegetables and complex carbohydrates), whereas she would normally only eat meat and chips. The mother felt this was because her daughter hadn't accepted that she had diabetes:

F: [She will eat properly] in the early morning when she hasn't got time to even think about it. And that's the only time she'll ever finish a plate.

M: The thing is [child's name] has got to accept that she's got diabetes, whereas she hasn't accepted that she's got diabetes.

In other cases, parents felt their child's externalising behaviour was reinforced by the parents' own responses, as in the case of D_7:

M: So, yeah I was so angry [when child refused blood test], and ... but the trouble is, the more I go on at him, it just makes him not want to do it more, sort of thing.

Parents generally were accepting and understanding of the behaviour if they thought it had uncontrollable physiological causes (i.e. 'hypo moods'). However, when they were unsure of the cause, they did not always feel confident in how to respond to the behaviour, as in the case of D_4:

M: I think probably, actually, we make a lot more exceptions for [child's name] when he goes into a bad mood, because of the diabetes. I think he gets away with more bad behaviour probably.

F: Half of the time it's nothing to do with the diabetes.

I: It's hard to tell sometimes though, isn't it?

F: Yes.

4.4.5.1. Summary of children's externalising behaviour and parent responses (Diabetes Group)

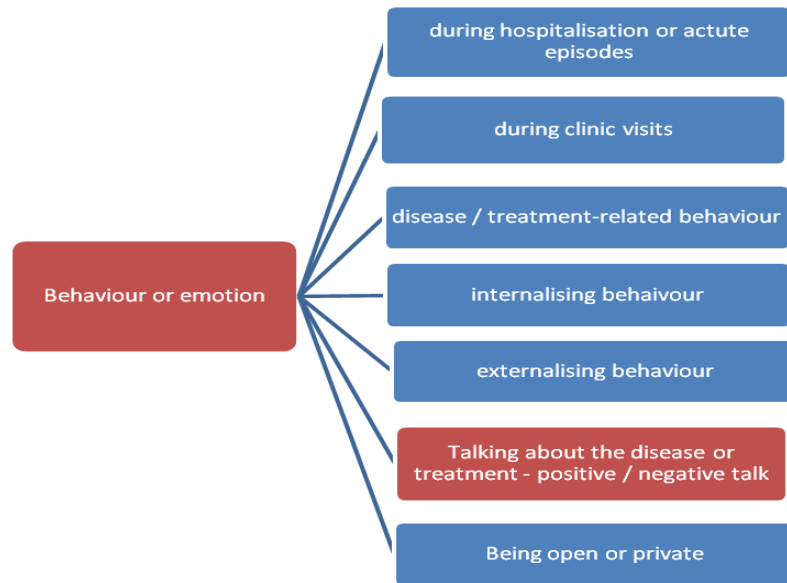
Child externalising behaviour was commonly described by parents in this sample, in particular anger, stubbornness / 'stroppiness' and argumentativeness. Since moodiness can be a sign of low or high blood sugar, some parents were uncertain about how sympathetically to respond to it. However, they did at times attribute behaviour, at least in part, to being a teenager, to a non-acceptance of having diabetes, to personality factors or the parent's own 'nagging' behaviour.

4.4.6. Child Individuality of Response - Behaviour or Emotion: Talking about the disease or treatment - negative and positive talk (Diabetes Group)

Few children were reported to express 'negative talk' about the disease, except the relatively typical 'I hate diabetes' or 'why me?' verbalisations described in section 4.4.1.1. These verbalisations were reported to occur rarely by two children (D_6 and D_12), and more commonly by D_3, D_9, D_11 and D_15. The parents of D_5 talked about their son wishing he didn't have diabetes so he could eat what he liked.

The main other area of negative talk related to the child not liking the attention other children gave them when they were self-administering or requesting help with treatment (D_5, D_8, D_13, D_14).

Only two mothers (D_6 and D_16) reported their child's positive talk, thinking they could be worse off than they were, or were uncomplaining.



Child Individuality of Response - Behaviour or Emotion: Talking about the disease or treatment – ‘negative’ talk and ‘positive’ talk: Example of ‘negative talk’

The following extract (D_14) was fairly typical of children who expressed dislike of unwanted attention by others. The child participated in this part of the interview.

Respondent	Interview extract
<p>D_ 14</p> <p>Negative talk</p>	<p>C: Daddy, I was in the class with [teacher’s name] when [peer 1’s name] was there, and she was talking to [peer 2’s name], and [friend’s name] was with me; [friend’s name] is a friend. And [peer 1’s name] just watched me doing my injection. She said, (made a face), and I got really annoyed.</p> <p>M: You should have told her to have gone out the room.</p> <p>C: She wouldn’t though.</p> <p>F: [Child’s name], has she had some education?</p> <p>C: No.</p> <p>F: Have you enriched her life?</p> <p>C: No.</p> <p>F: You have. Secretly, you have enriched her life. You’ve made her think, ‘Thank goodness that’s not me’.</p> <p>C: That’s what [peers 3 and 4 names] were whispering.</p>

Parents discussed how their child's not wanting the attention of other children was related to a desire not to appear different. Not wanting others to see them as different sometimes led children to avoid telling others about having diabetes or to avoid interactions with other diabetics. For example, the parent of D_9 said her child didn't want to go on sleepovers as she didn't want people to know that she had diabetes, and the mothers of D_7 and D_10 said their sons refused to go on hospital-organised trips for young diabetics. Similarly, the parent of D_7 reported that her child refused to go anywhere where he might have to inject in front of others. Others expressed annoyance when others watched or stared when they were injecting (D_14 above) or commented on the medical alert bracelet (D_8). One parent (D_3) reported that her daughter sometimes felt scared when reading about complication of diabetes, as her blood sugar was often high. This respondent, as well as D_13 and D_16 felt some regret their child had grown up earlier than they would have done had they not had diabetes.

Mothers sometimes expressed that their child didn't want to be 'clumped' with diabetics or known as a diabetic (D_10, D_15). Parents generally explained that their child disliked unwanted attention of other children (D_8), or were avoiding cruelty of other children (D15) or other children's misunderstandings (D_9).

Child Individuality of Response - Behaviour or Emotion: Talking about the disease or treatment – 'negative' talk and 'positive' talk: Example of 'positive talk'

An extract from respondent D_16 (reported below) was the most illustrative of 'positive talk'. The parent of the other child (D_6) said her daughter didn't get upset because of having diabetes, except when 'hypo', but occasionally says she wishes she wasn't a diabetic.

Respondent	Interview Extract
<p>D_16</p> <p>Positive talk</p>	<p>M: Yeah. I mean, he's been brilliant about it from the moment... I mean he's never complained about it from the moment he was diagnosed. I'm the one that's done all the crying and all the moaning, you know, and he's the one that's been, 'Well, it could be worse, you know.' And I think, 'Oh, from a twelve year old'.</p> <p>I: You don't feel like that though?</p> <p>M: Hmm. No, not really. (Laughs). Well I do, when you see things that happen to these poor children, you do think, 'Well, I am lucky, but I'm not as lucky as I'd like to have been!' (Laughs).</p>

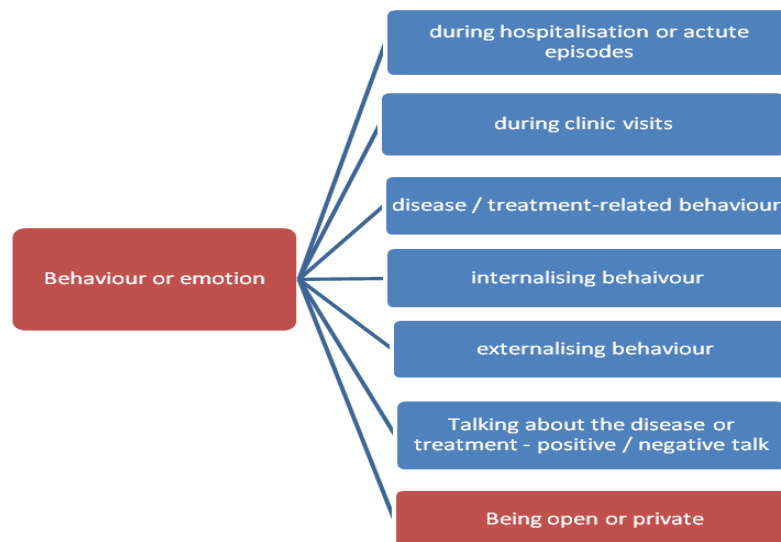
It is interesting to observe that the children expressing more positive talk were also those who were more open about their diabetes with others, as discussed in the next section.

4.4.6.1. Summary of children's 'negative' and 'positive' talk and parent responses (Diabetes Group)

In this sample, negative talk was more frequently reported than positive talk. Negative talk mostly related to the child saying they hated diabetes and that they disliked attention of others with regard to diabetes-related treatments and activities. This made them feel less normal, and they were sometimes teased or bullied by classmates. This resulted in the children sometimes avoiding being with other diabetics, for example on hospital-organised trips for diabetic youngsters. Parents' comments about their child's behaviour were mostly interpretations of their child's feelings, for example that the child just wants to be normal. Two parents expressed their upset that their child was unhappy being treated differently (D_9, D_15). Respondents D_14 encouraged their child to be assertive when receiving unwanted attention and the father praised her for her bravery.

4.4.7. Child Individuality of Response - Behaviour or Emotion: Being open or private about the disease or treatment (Diabetes Group)

Openness about the illness and treatment was related to positive or negative talk (as discussed in the previous section), as children who expressed more negative talk also tended to be less open (and vice versa). Specifically, the following respondents said their child did not generally like carrying out treatments in front of others, and / or avoided telling others about having diabetes: D_7, D_9, D_10, D_11, D_14, D_15. Those respondents who said their child didn't mind others knowing (particularly close friends) were D_1, D_2, D_3, D_6, D_8, D_12, D_13, D_16.



Child Individuality of Response - Behaviour or Emotion: Being open or private about the disease or treatment: Example of child being open about the disease or treatment

The respondents in the following excerpt were slightly unusual in their active encouragement of their child to be open about the illness and treatment, because they thought it was beneficial for both the child and others. One couple whose child was generally open, and had previously not given her own injections in public, said they now encouraged their child to do this openly for hygiene reasons, as they were concerned about their daughter going into dirty toilets to do it (D_8). Another respondent (D_6) viewed the child’s openness in a positive way, but did not actively encourage it. The remaining respondents whose child was open did not express whether they thought this was a good thing or not, and did not say that they either encouraged or discouraged it. In this excerpt, the child’s older sister (a teenager) participated in the interview:

Respondent	Interview Extract
<p>D_12</p> <p>Being open</p>	<p>F: It’s surprising how many people will avoid it. There’s a guy, because we go when [child’s brother] plays football, and we go to the football match every Sunday, and there’s one of the parents that comes along, and he has to walk away when she’s doing it. [injection]</p> <p>Sister: Yeah, she doesn’t like hide away.</p> <p>F: No, he just can’t watch. And we don’t tend to make her cover up. She’s kind of fairly open about it. She’ll think it’s good.</p> <p>I: She doesn’t mind other people seeing or anything.</p>

	<p>M: We've tried to encourage it.</p> <p>Sister: We've always said that she shouldn't be ashamed of it.</p> <p>M: Yeah, to let her think, I mean, rightly or wrongly, I suppose it's just a matter of opinion, but in our opinion, that's their problem, not [child's name's] problem. We never wanted her to feel that she had to go to the toilet to do her BM or do an injection. I just had this thought of somebody catching her in the toilets in the middle of an injection and them thinking she was a druggie, rather than a diabetic, and I thought if she could be open about it, and do her injections or BMs openly.....</p> <p>But different people have different views on that. I have debates with other friends that think we're wrong, and that we shouldn't do it in that way, but that's our view and that's how we've brought her up.</p> <p>I: She finds it OK at school, and she doesn't mind..?</p> <p>M: She's got the freedom to do it where she is, to go to a quiet corner or go to the medical room. It's her choice, and I think very often she goes and gets her bag and does it where she is. Yeah.</p>
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These parents attributed the child's willingness to be open to her early acceptance of the diagnosis, which was related to her being a young age when diagnosed, and also because she was a popular child with a supportive peer group. Hence, they said she coped well because of her very good peer support and acceptance. Similarly, respondent D_6 said her child was very young when diagnosed, to which she attributed the easy acceptance of having injections and being seen doing injections in front of others, which she viewed as 'normal'. This respondent also commented on her child's popularity and support from her peer group. Thus, the child's decision to be open about their illness may be related to their parent's positive attitude towards it, their early age of diagnosis and degree of popularity and peer support.

Child Individuality of Response - Behaviour or Emotion: Being open or private about the disease or treatment: Example of child being private about the disease or treatment

Parents frequently distinguished between their child being open with close friends, and being private generally (for example in front of strangers or classmates who were not close friends). The majority of children who were private in some settings were willing to carry out treatments in the presence of close friends. These respondents did not evaluate being private as either a good or bad thing to do, but supported their child's inclination. The exception

seemed to be where the parent felt it would be beneficial for the child, for example attending diabetes camps and outings, as in the case of D_7. The following excerpt (D_8) is typical of this group of respondents, who was happy to inject in front of friends, but didn't want to do PE or swimming because people could see her legs (with lipohypertrophy from over-injecting in single sites), although with increasing confidence, she has become more open in general. The child participated in part of this interview:

Respondent	Interview Extract
<p>D_8</p> <p>Being private – was self-conscious about appearance of injection sites</p>	<p>M: Yeah, that's another thing. I remember we went through the phase of her fingers were really sore. She didn't want to be injected because her legs were sore. Then we had the 'my legs are bruised' and you know, 'I can't wear skirts', 'can't do PE', and not wearing a swimming costume for swimming, 'cause everyone can see my legs'.</p> <p>C: PE at [child's school] is quite good, 'cause you can wear shorts in the pool, but I don't.</p> <p>M: I say, 'Just be honest'. Just tell them what it is.</p> <p>F: The point is, you've become more confident with it. It's become less of an issue.</p> <p>C: All my friends have seen me inject.</p> <p>M: Yeah, it's just part of life now, isn't it?</p> <p>F: I don't know, and obviously it would vary from person to person, but for us, I reckon the turn around point was probably about a year to 18 months.</p> <p>M: When [child's name] started injecting herself.</p>

Whilst parents reported that in general children did not mind close friends knowing about their diabetes and treatment, this was not always the case with other friends. For example, the teenage daughter of D_9 disliked people other than her close friends knowing about her diabetes, which led to her not giving her injection after a midnight snack during sleepovers:

Respondent	Interview Extract
<p>D_9</p> <p>Being private with less close friends</p>	<p>M: She's been very good with her injections, and I could never fault her on that. The only thing I used to worry about was if you're having a sleepover, and you're going to have a midnight snack, as [the diabetes nurse] would say, 'Have your midnight snack, but take some Actrapid as extra'. I never felt she was doing that, because I don't think at a sleepover, although it might not be your closest friends, you don't want people to know. That's what I did find. That used to trouble me.</p>

Despite this behaviour in a ‘sleepover’ situation, this respondent said that her daughter had been (and still was) happy for close friends to know, and that they would know what to do if she became ill. A negative aspect of being private that was highlighted by this parent was that not doing injections to avoid drawing diabetes to the attention of other children (especially not close friends), was evidently detrimental to the child’s physical health and illness control.

4.4.7.1. Summary of children’s being open or private about their diabetes, and parent responses (Diabetes Group)

In general, parents accepted and supported the child’s inclination to be either open or private. They appeared to understand the reasons for their child’s motivation and behaviour in this area; they did not frequently express their own feelings about this. However, openness was generally positively regarded and sometimes encouraged as being beneficial for the child and others.

The most generally open group of children (i.e. didn’t mind anyone knowing), were younger and had been diagnosed from a young age. The ages of these children at the times of the interviews were: D_1 (aged 9, diagnosed age 4), D_2 (aged 8, diagnosed age 3), D_6 (aged 8, diagnosed age 2) and D_12 (aged 12, diagnosed age 4). Additionally, the parents D_6 and D_12 described their child as mature, socially confident and popular, which may have led the children not to worry about injecting or doing tests in front of others. Two younger children wanted to be more private (D_5, aged 10, diagnosed age 2 and D_15, aged 8, diagnosed age 3). The parents of D_5 (who said their son had Aspergers) said the child didn’t like injecting in front of others because he would have to pull his trousers down. The parent of D_15 described her son’s significantly troubled behaviour and that he had been teased at school, so this may have contributed to his wish to be private. The parents of D_4, the only other younger child, did not discuss this specifically.

In contrast, parents who reported their child wanting to be private (or preferring only close friends to know) tended to be older and were often diagnosed at a later age: (D_7 (aged 15, diagnosed age 9), D_8 (aged 13, diagnosed age 11), D_9 (aged 16, diagnosed age 8), D_10 (aged 16, diagnosed age 11), D_11 (aged 15, diagnosed age 3), D_14 (aged 13, diagnosed age 9) and D_16 (aged 15, diagnosed age 12). The child’s wish to be private (particularly with those who were not close friends), tended to relate to wanting to fit in with peers and be ‘normal’ by not drawing attention to the diabetes. Some parents reported that as their child gained confidence in managing their illness, they also became more socially open about their

illness (as illustrated by the interview excerpt of D_8). Thus, there may be developmental as well as other psychological social factors that influence a child's wish to be open or private.

Where parents expressed worry, this related to their child's being private, as they were concerned about the health consequences (i.e. not doing an injection at sleepovers, injecting in 'dirty toilets').

4.5 CHILD INDIVIDUALITY OF RESPONSE - BEHAVIOUR OR EMOTION: COMPARISON OF ASTHMA AND DIABETES GROUPS

4.5.1. Behaviour or emotion during hospitalisation or acute episodes

It is important to recognise that these two groups of children experienced a different illness course and history, because the illness experiences directly influenced the child's behavioural and emotional responses. For example, the asthmatic children were typically diagnosed at about age 2, and had frequent admissions to hospitalisation with acute asthmatic attacks. This could account for why the most frequently described child behaviours of concern to parents related to anxiety, panic and uncooperativeness during treatments in hospital (e.g. venepuncture, nebuliser treatments). Many of these children were young at the time of hospitalisation and possibly had limited coping strategies. Therefore, they needed a significant amount of parental support during these experiences. Some parents felt more able to meet their child's emotional needs at these times than others; those who felt frightened themselves were less able to be supportive (which made them feel guilty), but those who were less anxious were able to respond more effectively (e.g. modelling more relaxed behaviour, being firm).

In contrast, diabetic children were often diagnosed in later childhood and were rarely hospitalised (except at the time of diagnosis). Therefore, few respondents described their child's behaviour during hospitalisation. Where they did so, child behaviour tended to be related to distress or other feelings about having the disease, rather than about the treatments *per se*. This may have been because most of the children were older at the time of diagnosis and had greater insight into the significance of the diagnosis. More typically, parents described their child's behaviour and emotion during acute episodes, particularly during hypoglycaemic attacks. Uncooperative or 'difficult' behaviour was commonly cited; parents did not always know how much of this was under the control of the child and felt frustrated and stressed when their child did not apparently listen to reason. It is likely that an important

element of the parents' stress would have been the knowledge of the consequences of the child not cooperating, i.e. that they could become comatose. A further contribution to stress may have been their child's exhibition of challenging behaviour at other times.

In some ways, it might have been easier for the parents to support the asthmatic children during acute episodes, as the children's fears (at their mostly younger age) related to more concrete and time-limited stressors (e.g. having blood taken, noise of nebuliser, fear of parental separation, etc.). Possibly the parents of diabetic children felt less able to respond effectively and have control in situations, such as when their child would not respond to reason during hypoglycaemic episodes, or when they expressed more profound worries (about the diagnosis). Furthermore, parents would have had little time to prepare themselves to support their child at the time of diagnosis, as symptoms presaging a diagnosis of diabetes are typically unexpected and abrupt (in contrast to those preceding a diagnosis of asthma).

Both groups of parents viewed very positively their child's acceptance and stoicism about treatment, but this was particularly evident with the asthma group. This was the only group of behaviours where parents did not feel they needed to actively intervene to support the child in some way, and they expressed pride in their child's ability to cope with their situation. It was notable that no parents (with the exception of A_16) expressed concern about their child's passivity during hospitalisation.

4.5.2. Behaviour or emotion during clinic visits

The experiences of the children in the two groups would have been similar, in that during the past year, they would probably have needed to attend clinic at least every three months. However, the asthmatic children would only be attending the hospital clinic if their asthma symptoms were hard to manage through normal GP appointments. Once a child's asthma becomes easier to manage, they are discharged from the hospital clinic into the care of their GP. Consequently, for some of the asthmatic children, clinic appointments may still have been a novelty; also, they might genuinely look forward to an improvement in their condition, and possibly even its disappearance.

In contrast, the diabetic children needed to attend clinic every three months throughout their childhood and adolescence; this long-term requirement could partly account for one adolescent's anger and reluctance to attend clinic. At diabetes clinics, children sometimes

needed to have blood drawn for HbA1c analysis, which could be distressing, whereas the asthmatic children did not normally have painful or invasive tests at clinic. The diabetic children could not look forward to a day when they might be rid of the disease; they cannot expect to ever stop doing their injections and blood tests every day, and must focus on preventing long-term problems that they can't imagine.

On the other hand, clinic attendance for asthmatic children and parents often meant that the child's condition improved, with possibly stopping medication and / or being discharged to community care. The exception in the asthma group was where an older adolescent expressed anger and upset about not getting better (as he and his parent had hoped). Some asthmatic children and their parents enjoyed coming to clinic because they had confidence in the doctors to treat them effectively, in contrast to their experience of community care. Thus, the child's and parents' expectations for the child's health and illness course could be an important determinant of their responses to clinic attendance.

The above differences could be grouped as 'disease-related'; however, there were also differences that could be grouped as 'developmentally-related'. The younger children may have been more likely to focus on the 'here-and-now', with parents discussing at interview about whether or not their child was cooperative or enjoying clinic attendance (for example, due to having time off school). In both groups, parents of younger children (or those recalling when their child was younger) discussed their child's upset at not understanding why they needed treatment or medication. In contrast, the parents of adolescents were more likely to discuss their child's feelings about the effectiveness of treatment or long-term implications of the illness. Connected to this in both groups of adolescents, were some reports of anger, upset and uncommunicative behaviours of older children and adolescents with clinic staff.

4.5.3. Disease / treatment-related behaviours and emotions

The most commonly-discussed area of behaviour and emotion in both groups was quite similar, but also subtly different. In the case of the asthma group, the child's wish to minimise the focus on the disease was identified, whereas in the diabetes group, this was described as taking responsibility for the illness or not. Both of these are characterised by approach and / or avoidance behaviours with regard to the illness. In both groups, many parents felt that avoidant behaviour was motivated by the child's wish to be 'normal'.

The reason for the subtle group difference in categorisation may be that in the asthma group, some children might be able to avoid carrying their inhalers with them when out with friends, or engage in strenuous sports, with perhaps no serious ill effects in the short term, and possibly even health benefits in the case of exercise. Therefore, a number of parents in the asthma group expressed ambivalence about this kind of behaviour, and were often sympathetic to their child's desire to be 'normal' by minimising the focus on the disease, perhaps more so in cases where the symptoms were less severe. The parents' beliefs about what was important in their child's development may also have influenced their ambivalent attitudes. If they prioritised good health and avoiding attacks, they were more anxious, for example, about their child doing strenuous physical activities; if they prioritised having a 'normal' childhood, then the concern about avoiding attacks was less evident.

In contrast, if the diabetic children did not look after their health (for example by avoiding eating or not taking a snack with them when out with friends) this could have immediate and serious consequences. Therefore, the parents focused much more on their concerns about 'irresponsible' behaviour, although from the child's viewpoint, this might have been motivated by a wish to be 'normal'. Parents however did vary in how seriously they viewed, for example, food transgressions, which like the asthma group, may have been influenced by their priorities for the child's development. On the whole however, parents in this group expressed more worry about their child's not taking responsibility, and also reported their child's dislike of being 'nagged' about these behaviours and the child's feelings and behaviours about 'monitoring their illness state'.

A minority of both groups of parents described their child's 'using' the illness to manipulate or gain attention, or to avoid doing something. Parents' emotions included anger, guilt at 'giving in', blaming the child and expressing helplessness. Where parents in both groups reported more positive behaviours in relation to self-care, they felt this was because their child chose responsible friends, were mature, developmentally ready to manage risks and didn't mind aspects of self-care. Examples of the latter included asthmatic children who were not 'sporty' and diabetic children liking healthy foods.

4.5.4. Internalising behaviour (non-hospital)

Internalising behaviour was reported by parents from both groups, although this was more commonly reported by parents in the diabetes group. In the asthma group, the most typical internalising child behaviour was being withdrawn and avoidant, followed by sleeping or

eating difficulties, and one case of depressed feelings. The parents of diabetic children more commonly reported their child's expressions of depressed feelings, although these were not necessarily persistent or extreme. Less typically, parents of diabetic children reported their child's withdrawn or avoidant behaviour.

In summary, similar behaviours were reported by both groups of parents, but the frequency of expressing depressed feelings was more common in the diabetes group, and withdrawal and avoidant behaviour was more common in the asthma group. It's possible that the unremitting character of diabetes and its unpleasant treatment accounted at least in part for this difference. Most asthmatic children (with an exception being the child whose parent said her son had been depressed) have some periods of the year when they are less troubled by their asthma, for example if it is seasonally-related. Also, asthma management does not involve inflicting pain on oneself, unlike diabetes management. Therefore, diabetic children may be more negative about their illness and also feel that the illness controls their lives.

In both groups, parents spontaneously discussed what may have accounted for their child's internalising feelings and behaviours. These included illness features (e.g. controllability), aspects of treatment and timing of diagnosis in interaction with other factors. These other factors included the child's temperament, personal characteristics, habits, developmental age, relationships with peers, friendships, and the presence of stressors additional to the illness (such as starting a new school).

4.5.5. Externalising behaviour (non-hospital)

In both groups, the most common form of externalising behaviour was being 'stroppy', characterised by argumentativeness, stubbornness and irritability. Parents of asthmatic children typically attributed this to frustration at physical restrictions of the illness in interaction with the child's temperament or developmental age (e.g. 'stroppy teenager' or too young to express feelings verbally). In one case, lack of oxygen to the brain as a prelude to an asthma attack was cited as an occasional reason for this behaviour. Parents of diabetic children frequently blamed 'hypo moods' for their child's behaviour, although they also said that sometimes this behaviour was unrelated to blood glucose fluctuations or was an interaction between abnormal blood glucose and the child's temperament or developmental age. Some of these parents were less certain about the cause of this behaviour, whether it was related to the blood glucose levels or not.

The parents of the asthmatic children were typically sympathetic with the child (recognising the child's lack of control over the physical restrictions). Also, the parents of typically younger children felt their child might not have been able to control their behaviour. Sometimes the parents of diabetic children were less sympathetic, particularly if they thought the child was 'stubborn' anyway or if they were unsure how much of the behaviour was under the child's control. Parents of diabetic children more often discussed how other life experiences (such as parental death or mental illness), or their own 'nagging' could contribute to their child's externalising behaviour.

4.5.6. Talking about the disease or treatment – 'negative' talk and 'positive' talk

Negative and positive talk was reported by parents from both groups, although those of the asthma group were more likely to report positive talk, and those of the diabetes group to report negative talk. Some parents in the asthmatic group discussed how they felt their child's 'sunny outlook' or forward-looking personal disposition enabled them to stay positive. Those who reported negative talk said this related to physical restrictions, illness features, drug side effects or prospects for their future life.

In contrast, only two parents in the diabetes group reported their child's positive talk (and the parent of one felt negative herself), and the majority of these parents (n=10) reported some negative talk by their child. Mostly this was comprised of expressions about hating diabetes, worries about complications or unwanted attention of others (which was related to not wanting to be different). Some parents in this group expressed sadness about their child's negative talk and underlying feelings, expressing their regret that their child had grown up too early because of the diabetes. As discussed in a previous section about internalising behaviour, it is possible that these group differences may relate in part to the unremitting nature, unpleasant and frequently overt treatment and permanency of diabetes.

4.5.7. Being open or private about the disease or treatment

Both groups of parents discussed their child being open or private, although the parents of the diabetic children more commonly discussed this. It is possible that this was less commonly discussed by respondents in the asthmatic group because it was less salient; fewer child treatment behaviours need to be demonstrated in a public arena. Where parents in the asthma group did discuss this, it mostly related to the child's wish to be private and not let

others know about their asthma, in order to appear 'normal'. This was a concern for parents who felt their child's health could be put at risk because of not telling others when they felt unwell, or in one case, taking too much medication because of wanting to use inhalers to seek attention.

In the diabetic group, some children wanted to keep their illness private, for example to avoid teasing or unwanted attention; these children tended to be those who engaged in more negative talk. Some parents expressed concerns about their child's wish to be private in some settings (e.g. not doing injections at a sleepover), although they acknowledged that this was connected to a wish not be different. Most parents said their child was open about their illness, but diabetes is probably harder to avoid making public than is asthma. For example, diabetic children might need about 3-5 injections per day, test their blood glucose several times per day and eat snacks at times when other children aren't allowed to have them (e.g. between meals and before exercise). This openness was on a continuum. Some children would only be open (for example giving their own injections) in the presence of close friends, whilst others would also be open with peers and / or in front of unknown people in general settings. Parents seemed to conclude that younger children, those who were diagnosed at a young age, who were popular, confident and mature, were more accepting of their illness and consequently more willing to be open. Some parents viewed openness in a positive way, whilst other parents did not express a viewpoint, supporting their child's inclination.

4.6 RESULTS AND DISCUSSION RELATING TO EFFECTS ON CHILD'S SOCIAL LIFE

In this section of the Chapter, the results of the analysis of second theme will be presented. As discussed earlier in this chapter, this theme was coded when parents discussed how their child's social and educational life was affected by having a chronic illness. It includes a description of parents' accounts of which activities were affected (if any) and why or why not, as well as how often any aspect of the child's social life was affected. Also, parents discussed how they and their child felt about limitations or lack of limitations in the child's social life.

4.7 EFFECTS ON THE CHILD'S SOCIAL LIFE: ASTHMA GROUP

All parents in this group made reference to the impact (or predicted impact) on their child's social or educational experiences with their friends at home or school, and also with their family. A detailed summary of the results of the analysis may be found in Appendix 4.5. The social activities were those where having asthma can affect the child's ability to participate. Parents' responses were categorised within these areas. In most cases, parents reported limitations in the child's social activity. Where the parent reported that there was no limitation (although there may have been previous limitations), the respondent code has been emboldened. Respondent A_10 was one of the two parents whose child was not in the hospital clinic sample, and A_1 was the child with Asperger's, who preferred not to socialise:

Social and educational activities with the child's friends at home or school:

- a) Playing / generally socialising with friends / going to parties or sleepovers (**A_1**, A_3, A_5, A_6, A_7, A_8, A_11, A_12, A_14, A_15, A_16)
- b) Sport or group physical activity (A_2, A_4, A_5, A_6, A_9, **A_10**, A_14, A_15)
- c) Attendance at school / pre-school (A_2, A_5, A_6, A_7, A_9, **A_10**, A_15)
- d) School or group trips, attending camp (A_5, A_6, A_7, A_11, A_14, A_15, A_16)
- e) Independent travelling to school (A_5, A_7)

Social activities with the family:

- a) Family trips out (A_5, A_15, A_16)
- b) Staying overnight at relatives' homes (A_1, A_5, A_9, A_11)
- c) Eating out in restaurants (A_1, A_8)

Appendix 4.5 lists the number of instances when parents referred to each of these social activities, and identifies the extent to which the children's participation in the social or educational activities was affected. Appendix 4.5 shows that a wide range of the children's social and educational activities were affected by their having asthma and that the children were not affected to an equal extent. Parents of A_5, A_6, A_7, A_8 and A_9 discussed more areas of their child's life, and were more likely to report that their child's participation in activities was either always / mostly always or sometimes affected. This was apparently distressing for some parents, as illustrated in the interview extract (A_8) reported earlier in this chapter (4.2.3.a. 'negative talk').

Whilst for most of these children, aspects of their social life were influenced either all the time or some of the time, in a few cases (A_3, A_10 and A_13), the child's social life was rarely or never affected. However, A_13 is only 2 years old, so will so far have had little social life experience with friends; A_10 was one of the children from the non-clinic sample, whose asthma was very well controlled and A_3 normally had fairly well controlled asthma and was old enough at age 16 to be responsible for her own medications. Thus, the impact of having good asthma control on children's social and educational activities is important to consider.

Two points are of relevance to explore when considering these results. Firstly, it is important to understand the *reasons* for the child's restrictions, as this may explain at least some aspects of the child and parents' decisions to institute social restrictions. Although one might initially assume that factors related to the illness might themselves be important, it is also the case that some parents implement more restrictions than do others, when the children seem to be similarly affected by asthma. There may be a range of person-specific reasons, such as variations in the degree of anxiety and judgements about health risks of various social activities. This may be important for parental adjustment, because if anxious parents impose more restrictions, they may experience more guilt and distress because of their actions.

Secondly, it is important to explore the *significance* of the social and educational restrictions for the child and parent. Some children were affected infrequently by certain social restrictions (such as staying overnight at friends' homes) whilst others were always affected (i.e. were never allowed to stay overnight). It's possible that the child with more extreme restrictions (i.e. never allowed to do the social activity) will have poorer adjustment than those with fewer restrictions, particularly if that activity is important to them. For example, some children didn't mind not doing sports, whereas others were upset by this restriction. It is reasonable to assume that if the child finds this upsetting, the parent will as well; this may have significance for parental adjustment. These two points will be discussed below.

Effects on the Child's Social Life: Reasons for restrictions

Reasons that parents gave for their child not participating in activities related to factors including concerns to avoid triggers of attacks, the effectiveness of the child's medications when developing symptoms and issues surrounding medication administration and the child's general health. Other reasons that were person-specific included how reliable the parent judged that the child would be to carry and administer their own medication appropriately, and the parents' anxiety and judgement about potential risks of the child undertaking the

social activity. These reasons may be broadly grouped as either illness-specific or person-specific; the nature and evidence of these will be discussed below.

4.7.1. Effects on the Child’s Social Life: Illness-specific reasons: The impact of illness severity and the nature and combination of triggers (Asthma Group)

Parents often indicated that the nature of the triggers for asthmatic attacks influenced whether or not the activity was restricted. For example, the asthma symptoms of child of A_1 seemed to be primarily affected by exposure to certain foods and animal dander. This mostly affected his ability to eat in restaurants or visit friends with pets, but had an insignificant effect on his ability to exercise. For example, he went on a hill walking expedition with his school, and coped well. In contrast, the asthma attacks of child of A_7 were triggered primarily by exercise, which limited her ability to play outside with friends. Therefore, the kind and number of social activities affected were influenced by whether or not the child’s asthma was responsive to the triggers associated with that activity.

For some children, particularly A_5, A_6, A_7, A_8 and A_9, a range of triggers seemed to be very significant, and this meant that greater numbers of social activities were restricted. For example, the child of A_5 was affected greatly by exercise, as well as by cold air in the winter (and respiratory infections) and pollen in the summer. Therefore, the number and range of his social activities all year around were affected. This was illustrated in the interview with the parent of A_5, where she describes how her child has no respite from his symptoms:

Respondent	Interview extract
<p>A_5 Child’s asthma affects him all the time and is getting worse</p>	<p>M: I think with [child’s name] asthma, because it has got worse and worse through the years, and his medication keeps going up and up and up, we haven’t had that [relief from symptoms]. We haven’t. And because his asthma is so much so that in the winter he’s affected obviously by colds and flus, and what’s going, and in the summer he’s more reactive to the pollen. So he doesn’t have a rest period in his asthma. His asthma is through twelve months of the year. So you don’t have that, ‘Oh great. It’s summer now. He won’t get a cold. He’s going to be good all through the summer’, because he doesn’t have that bit.</p>

Another illness-specific reason appeared to be how effectively the child’s medications controlled their asthma symptoms. For example, respondent A_5 above comments that her child’s medication was often inadequate; this significantly restricted many of his activities throughout the year. In contrast, the parent of A_3 reported that her daughter’s asthma

symptoms responded well to medication; therefore if she had her inhalers with her, she would not be restricted in any activities (including staying away in another part of the country with friends).

Other parents discussed that their child’s activity was only restricted when the asthma was ‘bad’; for example, the parent of A_7 only walked to school with her daughter (rather than let her run to school with friends) when the condition of her child’s chest was poor.

Finally, two parents (A_1, A_15) said that when their child was using a nebuliser (which was heavy to carry and needed an electrical socket to work), this restricted access to certain activities (e.g. picnics, school activity trips).

4.7.2. Effects on the Child’s Social Life: Person-specific reasons: The impact of parental risk assessment and anxiety on child’s social restrictions (Asthma Group)

It was evident that some parents imposed more restrictions if they assessed their child’s risk of engaging in a social activity as involving a significant trigger for an asthmatic attack. This is shown in the following interview excerpt below of the parent of A_11. It is interesting to note that this parent described her fear during some of her child’s emergency admissions to hospital for asthmatic attacks. It’s possible that these experiences, together with anxiety exacerbated by reading the magazine article she refers to, and perhaps his young age, influenced her decision to restrict his play opportunities with friends.

Respondent	Interview extract
<p>A_11</p> <p>Impact of parental risk assessment and anxiety</p>	<p>M: It’s not so bad at the moment because the weather’s OK for [child’s name]. But as soon as it starts getting better, it [asthma] gets so bad. I feel like I don’t want to let him out of my sight. I don’t think I’d ever let him wander off, do you know what I mean? Like, most kids will go out and play in summer and I’ve always got to be quite sure of where I know he’s going to be. I say, ‘Right. You stay in the garden.’ I don’t know what it’s going to be like around here in the summer, whether kids are out playing on the street or whatever, but I always want to know that he’s close by. Because I read a magazine too, where a little boy, it was actually a little coloured boy, about [child’s name]’s age, just went out in the street to play football with his friend and then his Mom had a knock on the door to say the little boy’d had an asthma attack, and it was too late. He’d died. I read that to [child’s name] actually, to try and frighten him, make him aware that he can’t go far, because he is asthmatic and he’s got to be near his inhaler. If I ever go anywhere and I’ve forgotten it, that’s another thing that scares me. Because you can guarantee if you go anywhere and you’ve forgotten it, you’ll need it.</p>

Child age may have been a factor influencing this parent’s decision not to let her child play far from her sight, as her child was not yet competent to independently self-administer his medication. In contrast, another parent (A_3), whose 16 year-old daughter had recently experienced a life-threatening asthmatic attack, imposed no social restrictions on her at all. This may have related to her confidence in her ability to self-administer medication, and also because her daughter’s friends knew how to manage the asthma symptoms.

Some parents (A_2, A_8, A_12, A_13 and A_16) did not offer, or intend in the future to offer a particular social activity opportunity because they predicted it would lead to an attack. For example, the parent of A_12 said her child had never stayed at a friend’s house overnight, and the parent did not intend to ever allow this. The reason she gave was because her son’s asthmatic attacks tended to occur at night. However, the parent of A_15 allowed overnight stays even though her son had night-time attacks as well. However, this parent reported that she was confident of the other parents’ ability to respond to her child’s asthma symptoms appropriately. Thus, factors that could inhibit a child’s social experiences might include a degree of over-protectiveness (influenced by different judgements when assessing risk) or possibly differences in abilities of friends’ parents to manage the illness.

A lack of trust in others may influence parents’ protectiveness and decisions to restrict social activities, as in the example of the mother of A_8, who did not trust chefs in restaurants to not serve food to which her son could be allergic:

Respondent	Interview extract
<p>A_8</p> <p>Impact of parental risk assessment and anxiety</p>	<p>M: I do not enjoy eating out. I want to go and eat out and I feel he should do it to make him feel normal, but I don’t feel comfortable. I have a knot in my stomach because we are completely reliant on somebody we’ve never met, in the kitchen, you know.</p>

4.7.3. Effects on the Child’s Social Life: Significance of social restrictions (Asthma Group)

As is evident in Appendix 4.5, the effects on children’s social and educational lives were meaningful for both children and their parents. Parents often reported that children were disappointed or upset by the social restrictions, some were distressed about being teased (A_5, A_6), and a number did not like feeling different from other children (for example, A_5, A_8, and A_14). Some children responded to difficulties in participating (for example

in sport) by avoiding it (e.g. A_15) whilst others continued to try, despite performing sub-optimally (e.g. A_4). Yet other children were reported by their parents not to 'mind' the social restrictions (e.g. A_6) or to have psychologically 'adapted' to these (A_14).

Some parents reported that they tried to compensate for these limitations by offering alternative opportunities, such as going to the play park and swimming instead of the activity centre (A_16), exploring the options for the child to go on a more local than distant school trip (A_8) or inviting friends to stay instead of the child sleeping at a friend's house (A_6). Parents did not discuss whether they felt that from the child's viewpoint, these alternatives compensated for their restrictions.

A number of parents expressed upset, disappointment and / or worry about their child's limited social or educational activities. They explained these feelings by saying they felt the child didn't have 'normal' childhood experiences (e.g. A_8), that the child would be less physically fit or have a lower quality of life (e.g. A_15), that they could be 'held back' developmentally (e.g. A_2) or could fall behind in school (e.g. A_7). In cases where children's social activities had increased (for example, due to improved asthma control), the parent expressed significant satisfaction. For example, the parent of A_9, whose son had recently taken up rugby and the trumpet, felt pleased that her son's physical health would likely benefit. Similarly, the father of A_8 (unlike his wife) felt a great sense of satisfaction when he saw his son enjoying his experience on the rare occasions when the family went out to a restaurant.

Therefore, restrictions in children's social and educational activities were of considerable concern and significance for many children and parents. Their responses in the face of these (or their child's reaction to them) may help to explain why there might be variations in parental responses that could be significant for their adjustment. It is possible that where children experience a smaller number of restrictions and where these are not all the time, and where the child does not 'mind' restrictions, the child would be less distressed. Parents in such cases may experience less concern, particularly if they are able to offer alternative experiences for the child.

4.7.4. Summary of effects on the child's social life (Asthma Group)

The analysis of data from this theme has shown that children's social and educational lives are affected to a varying degree, and over a wide range of activities. Many factors influence the number and extent of children's social restrictions including disease-related and person-related factors.

Disease-specific reasons included factors such as whether the social activity was associated with certain asthma triggers. Person-specific reasons included the child's motivation and determination and the child's interests. For parents, this included their anxiety about the activity, judgements about risks and their degree of trust of others (e.g. teachers or parents of child's friends), or not wanting to 'burden' others with their child's care.

Children varied in how they felt about and responded to these restrictions, with some experiencing significant disappointment, especially if the kind of activity was important to them. Where children were permitted to take part in activities that were difficult for them (e.g. sport), some children persisted despite problems, whilst others avoided the activity.

Parents' responses also varied, for example in relation to whether or not they allowed their child to undertake certain activities, whether they offered alternative options to the activity and also how they felt about the effects on their child's social and educational lives and their child's reactions to these limitations. They expressed both hopes and concerns about their child's past and future social life. Many parents felt they wanted their child to have as 'normal' experiences as possible, and were disappointed or upset when they perceived this was not possible. However, respondents sometimes felt pleased and proud when their child was able to overcome difficulties and to undertake the activities. Regarding future social activities, parents sometimes expressed how they hoped their child would be able to undertake certain activities in the future, or would not be held back in their development or education because of their asthma.

4.8 EFFECTS ON CHILD'S SOCIAL LIFE: DIABETES GROUP

All parents in this group made reference to the impact (or predicted impact) on their child's social or educational experiences with their friends at home or school, and also with their family. A detailed summary of the results of the analysis may be found in Appendix 4.6; it lists the number of instances when parents referred to each of these social activities, and

identifies the extent to which the children's participation in the social or educational activities was affected.

A range of social activities were reported where the child's ability to participate varied. Parents' responses were categorised within the areas described below. Whilst most parents reported limitations in the child's social activity, some said only the quality of the experience was sometimes affected. One parent said that having diabetes opened up a new sporting opportunity (sailing) (D_3).

Social and educational activities with the child's friends at home or school:

- a) Playing / generally socialising with friends / going to parties or sleepovers – some effect (D_1, D_2, D_5, D_8, D_10, D_11, D_12, D_14) or no effect in at least one of these areas (D_5, D_15)
- b) Sport or group physical activities – some effect (D_1, D_7) or no effect (D_3, D_10, D_16)
- c) Attendance at school – some effect (D_1, D_11)
- d) School or group trips – some effect (D_1, D_2, D_6, D_12, D_15) or no effect in at least one of these areas (D_6, D_9, D_10, D_11, D_13)
- e) Social activities in general – some effect (D_8, D_11), no effect (D_9, D_16) or positive effect (D_3)

Social activities with the family:

- a) Staying overnight at relatives' homes (D_5)

Effects on Child's Social Life: Reasons for restrictions

Some parents considered that the number and type of social activities their child was able to undertake were not affected, although sometimes the quality of that experience was affected; it was commonly reported by parents that whilst their child could undertake the same social activities as their age mates, there was less spontaneity in the experience. These children always had to think about what medical equipment or food / drink they would need to bring with them, how long they were going to be away for, and so on. Other parents reported that the number, type and quality of their child's social activities were affected. As with the asthma group, there were both illness-specific and person-specific reasons for this. However, whilst in the asthma group, disease severity was a significant factor accounting for individual variability in children's social lives, the characteristics of the diabetic children's disease varied less. However, a few parents reported that their child had more 'hypos' than other

diabetic children that they knew, which influenced their social and educational opportunities and experiences.

Illness-specific reasons reported by parents for restrictions to their child’s social life were primarily related to their assessment of other adults’ (or the child’s) lack of competence in detecting blood glucose changes, and or / lack of knowledge about how to avoid risks of high or low blood glucose and how to administer injections. Person-specific reasons included the parents’ finding that other parents and the child’s teachers’ anxiety about taking responsibility for the child, even though the parents themselves would have allowed the child to attend / participate in social events. These differences in the quality of the experience, and both illness-specific and person-specific reasons for restrictions will be discussed below.

4.8.1. Effects on the Child’s Social Life - Illness-specific reasons: The impact of illness variability (tendency to have more hypos) and in interaction with age, and insulin regime (Diabetes Group)

A small number of parents (D_1, D_12, D_15) described how their child sometimes had unpredicted episodes of hypoglycaemia or hyperglycaemia, and respondents D_1 and D_12 reported that this affected their child’s social life and also time off school due to illness. For example, the parents of D_12 said that their child’s school would not allow her to go on residential school trips without the parent because of the child’s frequent hypoglycaemic attacks. This was despite them allowing another diabetic child to attend; they said this was because the other child didn’t have frequent hypoglycaemic attacks. This was similar to the case of D_1 (excerpt below), where the child often had hypoglycaemic attacks at school, which would have been witnessed by his classmates, as described in the following excerpt:

Respondent	Interview extract
<p>D_1 Tendency to have hypos and impact on schooling</p>	<p>M: Oh no, I mean he has hypos. He does have hypos as a regular thing. He’s not one of these children who has never been a - what I call a bog standard tick along nicely diabetic. He’s more of one of these diabetics (gesture like hand on head). So no, he - you just sort of like, ‘Oh, your sugars are low, right, OK. Right, OK, let’s get some Coke, lets get some Lucozade. Lets, ‘Oh, which chocolate bar would you like?’ and then he goes..ohh’ (gesture like reaching quickly). (laughs) You just get on with it. It’s not, I don’t know. I don’t really think about it to be honest.</p>

Later in the interview, this parent describes how her child’s frequent hypos affect his school attendance and achievement:

Respondent	Interview extract
<p>D_1</p> <p>Tendency to have hypos and impact on schooling</p>	<p>M: I'm happy on the days he comes out [of school] and he's conscious. I'm happy on the days when we're not propping him up as he... There is nothing positive about [child's name's] schooling. It's affected his education. It's ... no. I can't think of anything at all positive, which is awful.</p> <p>I: It's difficult for you, actually.</p> <p>M: It's .. but there's little things, like he came out of school last year, and they'd had a spelling test. He came out and these kids were going, 'I got 48 out of 50!'. 'I got this' and 'I got that'. And [child's name] came bouncing out saying, 'I got 2!' And I said, 'Right or wrong?' And he said 'Right!' And he was so pleased with himself. And the teacher was just, 'Oh that is awful'. And I said to her, 'Well look, how much time has he missed off school this term?' And when you added it up, he'd missed about 5 or 6 weeks out of that academic term. And I said, 'For him - you can't knock him. He's happy that he's got, that he didn't get none.' But it's hard, because he's got two really intelligent older sisters, who get – [sister's name] is like 'super nerd'. (laughs). She doesn't practise for anything. She goes, 'Ttth got 100% again'. (laughs). So for him to then get an awful mark - which it was - terrible. But I wasn't going to say 'Oh, that's really bad', not when he, the teacher was sort of standing there and I was going 'Grrrh'. And all his friends were coming out and he came and he was so happy, that [child's name] got something right! (laughs) So...</p> <p>I: So, have they told you not to bring [child's name] back to school or he was just ill for a long time?</p> <p>M: He was - had a really bad bout of just 'not rightness'. Low sugars, upset tummy, and it just sort of toodles along, and when you add up sort of 2 days off here, and 3 days off there, and 2 days off there. And it all adds up. And that's when you realise, 'My God, he's missed a really big chunk'.</p>

This parent also reported that her son was not invited to birthday parties. Whilst she didn't say that a factor was her son's tendency to have a lot of 'hypos', this may have been a reason, as his classmates would have witnessed these symptoms at school frequently and presumably told their parents (who would be party hosts). The following excerpt from a later point in the interview illustrates this parent's view of how the child's diabetes affected his social life in regard to birthday parties, and her own feelings about this.

Respondent	Interview Extract
<p>D_1</p> <p>Not being invited to parties, limited playing at friends' homes</p>	<p>I: OK, right. How much would you say your child's illness affects his life?</p> <p>M: I mean, totally. He doesn't play at friends after school because their parents don't want him to play after school. Birthday party invitations stopped as soon as he was diagnosed. He never ever ever gets invited to a birthday party. He's been invited to parties, and I've said, 'You do know he's diabetic? What would you like me to bring?' And the invitation has actually been withdrawn.</p> <p>I: Oh dear.</p> <p>M: It does affect, it does affect your life. It does - the spontaneity has gone out of his life. There is no, 'I'll go and kick a football around with my friends' or 'I'll go and do this without forward thinking'. He always, and he is very good 'cause he will say, 'Can I do that?' He won't, or he'll think about it and he's say, 'I'm going to need an extra snack if I want to do that. He is very aware of the fact that he is diabetic and he is not the same as his best friend, who is asthmatic (laughs). He is aware, but by the same token, he's been snowboarding this weekend, he's been skibobbing this weekend, he's been swimming every day that we've been away on holiday. He does do what I think any other child would do on holiday but it's more controlled. It's a case of 'We won't go snowboarding before lunch, we'll go just after lunch'. So, I don't know.</p> <p>I: Yes, and I suppose when you were saying that some of the parents were withdrawing invitations, that's made a big difference. How does your son respond to that?</p> <p>M: He just says, he is really good, and says, 'OK'. Or he'll say, 'Well I didn't want to go to that party anyway'. But now he has a very close circle of friends who (3) small circle of friends (laughs) whose parents are happy for him to go, maybe for an hour, but after that hour, you come and collect your child. And, but for him he's grown up from the day he started school in that situation, so for him it's normal, it's not - it's nothing... Does that sound?</p> <p>I: Yes, yes, I understand what you're saying. How about you though - I mean that must have made you feel quite upset.</p> <p>M: It made me feel that, 'He's not an alien. He's not a three-headed anything. All I was asking was, if you're going to have sugar juice, would you like me to bring sugar free? Here's his finger pricker. If he says he's feeling low, can you ask him to check his sugars and give him something out of that (box)'. That was all. I wasn't asking them to do injections, or do you know what I mean? I wasn't asking, it was just a case of, I wouldn't ever ever put him into a situation where he could be in danger or something could happen that he could, you know, 'Here, have some real sugar jelly, followed by some real sugar Coke, followed by some bread and jam sandwiches' or whatever they have. And then that's not good for him. So that was all. And at the end of the day, if people are small minded and narrow minded enough not to want him there because they think they could catch diabetes or anything like that, then I'd rather he wasn't there. Because I don't want him mixing with people like that.</p>

	<p>I: Do some people actually think that - that they can catch diabetes?</p> <p>M: Oh yes, I've been asked.</p> <p>I: By school friends' parents?</p> <p>M: Yes, 'How did you catch it?' 'Oh no, actually you don't catch it. It's genetic - he was born with it'. And then we've had people saying, 'You must have fed him a lot of sweets!' And it's just ignorance and unless people are educated, they won't know.</p>
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In addition to possibly other parents' worrying about whether diabetes was contagious, and the tendency of the child to experience a lot of hypos, it's possible that the above child's limitations in self-care affected other parents' willingness to invite him to social events such as parties; the inclusion of these children in school trips may have been affected for these reasons (in addition to the child's tendency to have frequent hypos), as described by D_1 and D_12. Where these younger children were permitted to go on school trips, this was usually with the proviso that they were accompanied by the child's parent, but this difficulty was not reported by parents of older children.

The lack of the child's self-care skills reported in the above excerpt could have been related to his age. He was still quite young, and unable to administer his own injections and fully demonstrate understanding of self-care. This was in contrast to the experience of most of the older children; for example, the parents of D_8 described how their child's self-sufficiency in managing her treatment enabled her to stay with her godmother overnight, even though the latter was very anxious about having her stay.

Finally, one illness-related factor that could affect the quality of the child's social life is their insulin regime. A number of the older children were on an insulin regime called 'basal bolus', which meant they could vary the injection time and volume of insulin according to when and what they ate, and their activity level. This meant, for example, that at a sleepover or birthday party, they could inject after having party food with their friends at an unusual time or after unusual types and quantities of food. For example, D_7, although an adolescent, was still on the traditional fixed-time insulin regime and the parent said this stopped him from going out sometimes because the activity would coincide with his injection time.

4.8.2. Effects on Child's Social Life: Person-specific reasons: The impact of parental risk assessment and child age on child's social restrictions (Diabetes Group)

As discussed in 4.8 above, some children were able to engage fully in a wide range of social activities, with limited or no restrictions, provided they were in a supervised context where adults were knowledgeable about symptoms and management of diabetes (for example at school), or where the child was completely confident in self-caring. However, the children did need to organise and plan social activities more closely than would other children. This was because their medical management required them to take with them on outings a range of items such as food / glucose tablets, blood testing equipment and insulin injections.

The following example was selected as it illustrates in the first part of the excerpt, the common finding that parents reported their child enjoyed a good social life, but the quality of the experiences may have been affected – for example having attention drawn to their illness or experiencing a lack of spontaneity. The second part of the excerpt illustrates a second common finding, that in cases where the parents reported some restrictions to activities, this was often because other parents were either not willing or not able to cope with symptoms or treatment. This is shown in the contrasting experiences reported by the parents below – the mother says that her son does all the things a normal child does at school, but later in the interview says he hasn't yet been on a sleepover, although his non-diabetic brother had done so by this age. This seemed to be because at school, the school nurse had been giving him his injections, whilst at a sleepover, no parent they knew would give an injection.

Respondent	Interview Extract
<p>D_4</p> <p>The influence of context on child's social life</p>	<p>I: So, how much would you say [child's name's] diabetes affects his life at this point - or not that much?</p> <p>M: I don't think - he does all the things a normal child does at school. He has a little black bag that he carries with him, with his glucose. He's got one of those orange injections in case he goes - we've never had to use it fortunately. He knows now that if he feels funny, he takes a glucose tablet. So that's very good. And he takes that everywhere with him, on the games field and everywhere. So he does everything else that all the other kids do.</p> <p>F: He must get very pissed off with everybody asking him, 'Did you have a good lunch? Did you have a snack this afternoon?' And I don't necessarily believe he tells you the truth - he just says, 'yes, yes, yes', because he gets fed up being asked.</p> <p>M: His teachers do - you know the teachers sit at the table - and they do make sure that he eats properly. But he eats very well at school. Yesterday, he had three lunches he told me!</p>

	<p>I: And his school friends - there's not any issues?</p> <p>M: It's not an issue. The only thing is I have to be a little bit careful, maybe if he goes to visit someone, that they're aware of it, that they have our contact numbers. He hasn't had any sleepovers, which [brother's name] certainly did by this age. So as he gets a bit older, I think it'll become more of an issue.</p> <p>I: Is that your concern or his, or because of the other parents?</p> <p>F: You can't find anyone to do an injection.</p> <p>M: I don't know that a parent could do an injection, if he goes to stay over.</p>
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In the case of some older children, the reason for not taking part in social activities seemed to be related to the child's choice (D_7, D_10), due to not wanting to draw attention to the diabetes, rather than other people refusing to include them in social activities. In other cases, the parents' problem-solving and advance planning was important in enabling the child to have as normal a social life as possible (D_5, D_6, D_13, D_16). The following example is illustrative of this finding:

Respondent	Interview excerpt
<p>D_13</p> <p>Importance of parent advance planning and problem-solving skills for child's social life</p>	<p>M: She actually went to the Isle of Wight for a week in the July. I had to write a step-by-step guide to what she needs to do, and how much insulin she was taking, you know, everything....I went down to school at the end of May and I said, 'Look,' I said, '[child's name's] going to the Isle of Wight with you.' And they said, 'Yes, don't worry. We know all about diabetes; rest assured, she'll be alright.' (In patronising voice). And I thought, 'OK, fine.' (In surprised, disbelieving voice). Two weeks before she went, they were panicking. 'What's she.. what....ahh.' And I said, 'What, I thought you were trained?' And they went, 'Oh, ahhhhh.' And I thought, 'Well, so much for first aid!' (Laughs). So, as I said, I wrote an A4 step-by-step, and she was fine. She was fine. I had to be careful how much activity she did, to make sure she didn't have a hypo, but she had her biscuits in her bum bag and everything else, and the glucose tablets so, yeah, she knew what she was meant to do and what she wasn't.</p>

4.8.3. Effects on the Child's Social Life: Significance of social restrictions (Diabetes Group)

Whilst all the diabetic children and parents had to plan social activities around the child's treatment, the limitations on the child's social life varied, as indicated in Appendix 4.6. For many parents, their experience was that the child's diabetes had little or no effect on at least some of the child's social activities (respondents D_3, D_5 D_6, D_9, D_10, D_11, D_15,

D_16), but only 5 of these parents reported no significant effect on their child's social life in any area (D_3, D_5, D_9, D_15, D_16).

Nevertheless, in all cases, the quality and / or spontaneity within the activities were affected to some degree. For example, some parents thought that the quality of the child's experience on a school trip was affected by the parent having to accompany the child.

It was evident that some parents were very motivated to minimise the impact of diabetes on their child's social activities, and used effective planning and problem-solving skills to facilitate their child's activities. Some parents expressed their pleasure in being able to help their child engage in normal activities, experience a degree of developmentally appropriate independence and / or support the child's wish to not be different (D_2, D_6, D_9, D_11, D_15, D_16).

A number of parents reported that their child's social activities were affected significantly in at least one area (D_1, D_2, D_5, D_7, D_8, D_10, D_11, D_12, D_14). There was a tendency for these activities to be those where others would have to take responsibility for the child's treatment or know how to detect and respond to a change in the child's condition. Parents did not often report that their child was distressed or disappointed by restrictions such as not being invited to birthday parties. The parents had varying responses to their child's social restrictions, which partly depended on who decided whether the child could participate or not.

Sometimes the parent would have allowed the child to go to parties or on school trips without accompanying them, but teachers, parents or others wouldn't allow this. In these cases, parents were sometimes accepting of others' reluctance (D_2, D_8, D_11); others were disappointed, resentful, angry, upset or frustrated at their child's exclusion or lack of opportunity (D_1, D_12, D_15). Parents, particularly of younger children, were disappointed and regretful that their child was missing out on normal aspects of experiences. For example, the mother of D_12 discussed her feelings about the need to always accompany her child when on school day trips:

M: 'I'd always have to go, and happy as I was to do that, I sometimes felt it was necessary for [child's name] to experience these things, these outings as part of, you know, growing up, without one of us being there.'

In other cases, the parent did not allow the child to take part in an activity because they lacked confidence in others (D_2, D_14), or else if they allowed them, they worried about them

during the activity (D_2, D_3, D_11). In a case where it was the child's choice not to participate (not wanting to have to do an injection in front of others when away), the parent was disappointed that the child let the diabetes control him (D_7). Finally, there was some evidence that parents felt they benefited themselves by their child being away on school trips, as they got a break too (D_11, D_12).

In summary, although most children did experience some restrictions in their social life, particularly in relation to the quality of their experiences, few children seemed to have been distressed by these limitations. However, where the parents felt that others were unreasonably restricting the child's opportunities, the parent experienced anger, resentment and other strong emotions. Where parents had more control over the situation (i.e. where they made the decision not to offer the opportunity), this was often related to a lack of confidence in others' competence. Therefore, the parents' feelings about control over their child's social life might be an important factor in determining the parents' emotional responses to children's social restrictions.

4.8.4. Summary of effects on the child's social life (Diabetes Group)

The findings demonstrate that most children experience some impact on their social life, particularly in the quality of their social experiences (such as the potential for spontaneity). Both disease-related and person-related factors influenced the degree of restrictions or potential for achievement that the child experienced.

The main disease-specific reason was whether the child had a tendency to have a lot of 'hypos'. This tendency appeared to influence others' willingness to take responsibility for the child during social activities and also affected their schooling. Person-specific influences included the child's age (which was related to their ability to inject themselves, for example) and whether others were able to take responsibility for the management of the child's health and treatment when away from parents.

Although parents rarely reported that their child was upset by social restrictions, the parents themselves experienced varying emotions. Sometimes, parents felt that the reason for the restriction was the fault of others; in these cases, they often experienced anger, frustration and resentment. In other cases, parents themselves imposed the restriction because they did not believe that others could manage their child's illness, or if they did allow the child to

participate, they worried about them whilst they were away. Parents were generally very pleased when they were able to support their child to experience developmentally-appropriate levels of independence (for example going on school trips without the parent accompanying them) and normal social functioning.

4.9 EFFECTS ON CHILD'S SOCIAL LIFE: COMPARISON OF ASTHMA AND DIABETES GROUPS

More parents in the asthma group than in the diabetes described significant limitations in their child's social life as a result of their illness and treatment. It seems that this is related to a number of factors. Firstly, many child social activities seem to be directly influenced by asthma symptoms or triggers to those symptoms (such as sport, singing, visiting others with pets, eating in restaurants and so on). Also, the number and nature of the trigger(s) for the child influenced the number of social activities in which they could participate.

In contrast, children with diabetes can do all of these things provided that they are well prepared and plan in advance. For example, diabetic children can engage fully in sport so long as they remember to eat something beforehand and have their glucose tablets readily available; in contrast, the asthmatic children in this sample often could not manage strenuous exercise, even when taking their medication. These findings could perhaps account for why parents of the asthmatic children more often reported that their child was distressed about social restrictions and why they tried to find ways to compensate for them.

Another factor that might account for this variability was the predictability of illness symptoms. Whilst a few diabetic children had a tendency to have a lot of hypos, this pattern was recognised by parents. Consequently, parents of diabetic children might have reasonable confidence in allowing the child to participate in activities if they thought the child's health was not in danger. However, many of the parents of asthmatic children reported unexplained and unpredicted asthmatic attacks. In some cases the trigger was unknown, and some of these attacks had been life-threatening. This could affect the parent's confidence in allowing their child to participate in activities in their absence, and their feelings of control.

A further influence seemed to be the degree of effectiveness of the medication. For some asthmatic children, their medication was not always effective in relieving their symptoms, often leading them to need hospital admissions. This is likely to have affected both the quality of the child's experience when participating in activities (such as sport) and the

parents' degree of protectiveness. A problem of poor medication effectiveness was not however reported by parents of diabetic children.

Both groups reported variations in the quality of their child's social experience. For the diabetic children, this was often related to the preparation required prior to a social activity, due to the need for significant advance planning and problem-solving. This is because of the complexity of the child's treatment regime, involving blood tests, insulin injections and food intake at specific times. The preparation by asthmatic children was not as salient, as they mainly needed to check if known triggers would be present, and take their inhaler (and less commonly, also a nebuliser and/or Epipen) with them. For the asthmatic children, the experience itself rather than the preparatory phase tended to be affected (e.g. not being able to run as fast as others).

Both groups of parents however experienced other people's reluctance or inability to recognise significant changes in their child's health condition and / or to manage the child's treatment. This was an important reason for restrictions in the child's social life in both groups. Some parents from both groups experienced frustration and resentment as a result of others' lack of competence, understanding or willingness to support their child's treatment needs. Also, parents in both groups were concerned that their child had as normal a social life as possible and was able to achieve developmentally-appropriate levels of independence. Where it was possible to overcome obstacles and support their child in this way, parents expressed satisfaction in this achievement.

4.10 RESULTS AND DISCUSSION RELATING TO THE CHILD'S RELATIONSHIPS WITH FRIENDS, PEERS AND AT SCHOOL

This section of the chapter will examine the results of the data relating to the child's experiences with friends or peers and at school. It will include parent reports about the nature of their child's friendships, how friends were supportive or not, and sources of difficulty with peer relations and at school. In addition, it will report parents' perceptions of their child's feelings about these experiences, as well as their own feelings and responses to the child.

4.11 CHILD’S RELATIONSHIPS WITH FRIENDS, PEERS AND AT SCHOOL: ASTHMA GROUP

Seven participants made reference to how their child’s asthma influenced their child’s relationships with friends, peers and at school (A_2, A_4, A_5, A_6, A_8, A_9 and A_15). Some parents did not feel that their child’s friendships or peer relationships were affected by having asthma (A_2, A_9). A few parents referred to the behaviour of friends, for example teasing or having unwanted attention (A_5, A_6, A_15) because of their child being different; other friends were supportive and could be relied on to respond to emergencies appropriately (A_8, A_15). Finally, wanting to do ‘normal’ things with friends was a motivating factor for some children (e.g. A_9).

One child (who had been teased) (A_6) changed her friendship group, including developing a close friendship with a diabetic child (who was also ‘different’). Her parent reported that she also responded by trying to compensate for being different, as shown in the excerpt below.

Respondent	Interview extract
<p>A_6 Adolescent girl</p>	<p>M: You know, she’ll try and make herself look more wacky than all her friends. And I’m sure that’s sort of trying to cover up and compensate for the fact that she feels different in other ways as well.</p>

Generally, when children experienced difficulty in peer relationships, parents recognised that it was hard for the child, and felt sorry for them (e.g. A_5), but when friends were supportive, this reduced parents’ anxious feelings (e.g. A_8).

4.11.1. Summary of child’s relationships with friends, peers and at school

Parents reported both positive and negative aspects of relationships with friends and peers. On the positive side, some parents felt that their child’s relationships were not affected at all and friends often offered support to the child, including being willing to provide treatment as needed. This helped to reduce stress for parents. However, where children were teased or received unwanted attention, this led to distress for both the child and parents. Children responded in different ways to difficulties in social relationships, either by establishing new friendship groups or trying harder to join in with their friends’ activities. Parents evidently were pleased when their child had a good group of established friends.

4.12 CHILD'S RELATIONSHIPS WITH FRIENDS, PEERS AND AT SCHOOL: DIABETES GROUP

The parents of nine children discussed their child's relationships with friends, peers and at school. Most of the parents spoke about the positive experiences relating to their child's friendships – that the friends were supportive, understanding and reliable (D_2, D_3, D_6, D_12, D_16). Parents of four children reported some less positive experiences (D_1, D_12, D_14, D_15), including teasing and being made to feel different.

The following is a typical example of parent description of positive and supportive friendships, in the context of some difficulties at school:

Respondent	Interview Extract
<p>D_12</p> <p>Positive friendships in the context of some school difficulties</p>	<p>Sister: She really loves raw pepper and raw carrot and stuff; we used to cut it up and put slices in her lunch box. She got picked on for that too, didn't she?</p> <p>M: That's a point really, that we ought to raise to you, yeah. Eating at school at lunch time, that has been a problem.</p> <p>Sister: Yeah, she wouldn't have a chocolate bar, she'd have fruit or something. And I think she's felt differently.</p> <p>M: She'd definitely felt differently at lunch time.</p> <p>Sister: And the fact that, because they're not allowed to have biscuits or cakes or anything at break time. They have to have a piece of fruit, but [child's name] sometimes needs to have a biscuit, and she's felt different then as well.</p> <p>F: I think what's helped in that environment is her little circle of friends. And she is quite popular, so while she might feel a little uncomfortable being maybe picked on slightly, I think if she was an unpopular kid, that would be dreadful. That would be absolutely awful.</p> <p>Sister: Because they'd have a target.</p> <p>F: Yeah.</p> <p>M: Yeah, definitely.</p> <p>F: She'd be crucified.</p> <p>I: But she has supportive friends.</p> <p>F: She has a very nice little circle of friends, one in particular who's very close to her and is, what I said earlier, if there's one family that she can stay with, it's her Mom and Dad, her best friend's Mom and Dad, who are close friends with us as well, who she'll go and stay with. But there are others as well. I think she's got a nice little circle of friends.</p>

	<p>I: Hmm. So it sounds like in general, you feel pretty positive about the school relationships, but have some frustrations when some teachers don't understand how to deal with it or don't seem to have the motivation to find out.</p> <p>F: Older frustrations now, because [child's name's] got that much more able to cope with it.</p> <p>M: Yeah. But when she needed the care of an adult, particularly when she was younger, it was more frustrating.</p> <p>F: Certainly for the purposes of what you're doing, now, it's certainly something to consider for younger kids first coming into school, as being...</p> <p>M: They're at school more than they are at home, aren't they?</p> <p>F: Exactly.</p> <p>M: Sometimes she was walking away from school, many a time and bursting into tears.</p> <p>F: They've got to feel confident.</p> <p>M: Yeah. Loads of times.</p> <p>I: Was that because of the teacher's attitude basically?</p> <p>M: Yeah, just feeling that they didn't have an understanding, a real understanding of their care, she cried.</p> <p>F: And then feeling frustrated that they can't get a point across and they'll end up putting up with feeling awful for the rest of the day, because she didn't feel like she could go and speak to a teacher.</p>
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Evidently, this child had the social skills, coping strategies (including using supportive friends) to deal with problems at school, particularly now that she was older. These parents felt positively about the child's supportive friendships, which they considered to be at least in part due to her popularity. Other parents reported that friends were helpful because they were involved in and knew about the child's treatment (so could, for example, recognise a hypo) (D_3, D_9), protected their friend from unwanted attention (D_16) or were just accepting about the child's need to have snacks or injections (D_2, D_6).

The next extract is of a younger child who was less able to cope with problems and school, and had a less supportive peer group. This parent evidently was concerned about her son's ability to cope well with being teased for being different.

Respondent	Interview Extract
<p>D_14</p> <p>Teasing for being different, poor coping</p>	<p>M: And at school, they've been very good, but kids are cruel sometimes, and sometimes there's been the odd comment about 'You're weird', but I said, 'you know, that's just...' But he takes it all to heart, and it takes it all as personal, and he so wants to be like all the other boys. And in his little mind, he doesn't think he is, because, you know, he has to have a snack twice a day, the other kids don't. He went through a phase when he wouldn't eat. He wouldn't eat, so they kept him in to eat. And I said, 'Well, no, he has to be treated like the others. I don't want him being made, you know, treated differently, because that isolates him from the others.'</p>

This kind of report was less common, but similar comments were made by the parents of D_14. Also, one child (D_1), who had not been invited to friends' parties or homes to play, developed a small circle of new friends which included another child with a different chronic illness.

4.12.1. Summary of child's relationships with friends, peers and at school (Diabetes Group)

Most parents reported that their child was well supported by friends, which helped them cope with the stress of having diabetes, and with others' responses to them in relation to their illness or treatment. Where the child experienced positive friendships and peer relations, parents felt positive about their child's experiences in this context. Most of the negative experiences with friends and peers related to being teased for being different. Parents encouraged the child to stand up for themselves, and / or took steps to minimise differences in the child's school experience.

4.13 CHILD'S RELATIONSHIPS WITH FRIENDS, PEERS AND AT SCHOOL: COMPARISON OF ASTHMA AND DIABETES GROUPS

The parents' reports of their child's experiences with friends, peers and at school were similar in both groups. A source of stress for a number of children (particularly younger children) was feeling different because of their treatment or symptoms, and being teased about this by peers. In many cases, children's strong friendship groups helped them to cope with such experiences. Friends also provided support by being involved in symptom recognition or treatments, protecting their friends from unwanted attention and / or just being accepting. This was evidently appreciated by parents, who recognised that this helped their child to cope.

A smaller number of children were reported to experience less positive peer relations (often also related to them feeling different). In response to this, children occasionally formed new friendship groups, tried to be more like their friends or just became upset. This was a source of some worry for parents, who responded in different ways including encouraging the child to be assertive or attempting to minimise the child's experience of feeling different.

4.14 GENERAL DISCUSSION AND IMPLICATIONS FOR THEORETICAL MODEL

Within this general discussion of the findings of this Chapter, findings relevant to the development of a coherent model of parental adjustment will be explored, including relationships between different aspects of parents' experiences. This is central to research objectives 5-8, identified in Chapter 3, which relate to asking questions of the data, examining the concept of adjustment and its meaning for parents, and identifying what might influence individual variability in parent adjustment. However, the explicit focus in this discussion will be on findings relating to the first research objective, namely 'Examine similarities and differences in parents' perceptions of the impact of the illness on the child's emotional and social life; consider how these perceptions influence parents' practical and emotional responses'. Consideration of this objective in the context of the findings has led to the emergence of some key questions including, 'How do parents perceive their child's adjustment to the illness?', 'How does the nature of the child's response to the illness relate to parents' adjustment?', and 'To what extent do disease-specific and individual differences influence child and parental adjustment?'. These questions will be used to help frame the body of this discussion.

Throughout the discussion, reference will be made to schematic diagrams found in Appendices 4.7-4.16. As explained in Chapter 3, these were developed as an outcome of the data analysis, and illustrate key findings relevant to parent adjustment and show possible influences on parents' reported outcomes. As explained in Chapter 3 (Section 3.4.2.4), specific symbols, colours and directional arrows have been used in order to facilitate expression of meaning and highlight influences. The Chapter will end with an overall conclusion relating to the insights for the theoretical model that have been gained from undertaking this process.

When examining the similarities and differences in parents' perceptions of the impact of the illness on the child's social and emotional life, it was evident that an important aspect of parents' view of their child's adjustment related to the child's behaviour, and how adaptive they believed it to be in particular contexts or in general. Parents seemed to have a fairly consistent idea of what was adaptive child behaviour in acute care or clinic situations (for example, coping with stressful events and cooperating with treatment), as well as in general (particularly being able to do what other children do, and not consistently exhibiting behavioural problems). Some parents described child behavioural problems as only occurring temporarily and in specific situations (e.g. hospital or clinic), and that outside these times the child was seemingly adjusting well. Other parents saw these child behaviours in a more general way, believing they reflected deep-seated and enduring adjustment problems. Positive behaviours were similarly described as context-specific or generalised.

Behaviour and emotions in context-specific situations (hospital, acute episodes, clinic)

One group of context-specific behavioural descriptions was in a treatment management context, for example during hospitalisation or clinic attendance (i.e. the behaviour was elicited by the circumstances, and might not represent adjustment in general). In Appendix 4.7 on pages 65-66, Schematic Diagrams 1a and 1b reflect experiences of two parents from the asthma group during hospitalisation, where children were young (A_7 and A_16); however, some of the features of 1b were reported by other parents of asthmatic children as well in their efforts to prevent hospital readmissions. Experiences of this type were not described by parents in the diabetes group because very few were hospitalised and most of the children were not very young. Therefore, it is possible that some aspects of these findings could be applicable to this group as well, where these two variables are present.

Of interest to note in Diagram 1a is that parents expressed their beliefs concerning how external factors and/or their own behaviour may or may not have contributed to good or poor child coping in particular situations. These parents expressed how their own emotions affected their fear of or worry about future hospital admissions, leading them to take apparently extraordinary measures to avoid future hospitalisations (as shown in 1b). Some of these measures (such as restricting the child's activity, or over-monitoring their respirations) might not have been optimal for the child's adjustment. Furthermore, parents may also have resorted to such extraordinary preventive behaviours when their actions did not result in reduction of hospital admissions; parents may feel increased stress due to feelings of low self-efficacy.

In contrast, in Appendix 4.8 on page 67, Schematic Diagram 2 (reflecting the experience of A_2) illustrates that where parents of similarly aged asthmatic children in hospital feel capable of supporting their child (e.g. because the parent does not fear needles), they may feel more empowered to support their child, and the outcome may be more positive. This point is relevant when considering the question about how the child's response to the illness relates to parents' adjustment. Parents may see child adjustment as partly related to their own actions, or how they have personally coped or adjusted in particular situations. In some cases, other factors influence the parent and child's coping (for example the mothers' perception of medication effectiveness). These schematic diagrams illustrate that a complex interplay of procedural and environmental events, medication effectiveness, illness history, parent and child coping contribute to adaptive behaviour of the child in specific contexts. It highlights the importance of considering and addressing parent fears and concerns and coping strategies in acute situations.

Similar points may be made in relation to Appendix 4.9 on page 68, where Schematic Diagram 3 relates to behaviour during clinic attendance; the age of the child / adolescent, medication effectiveness, illness history and parent's feelings about ability to support the child were all important elements and influences on child and parent feelings of competence and control, which would be beneficial for adjustment of both. Whilst diagram 3 is primarily illustrative of the experience of A_5, some of the elements were reported by other respondents (e.g. asthmatic adolescent's frustration at low medication effectiveness and resultant activity restrictions related to 'difficult' behaviour at clinic).

On the other hand, in Appendix 4.10 on page 69, Schematic Diagram 4 shows that when these factors are not as influential (e.g. medication is effective), and where positive features are present (e.g. toys), the child enjoys and is more cooperative at clinic, and both parent and child feel confident in managing their situation. Also, although the diagram focuses on some parents' experience within the asthma group, some of the same points were reported by parents in the diabetes group. For example, the child of D_7, an adolescent who had been diagnosed many years previously, expressed anger at clinic; similarly his diabetes was poorly controlled and his parent found it challenging to manage this behaviour. These two diagrams therefore illustrate the importance in both illness groups of offering developmentally-appropriate support to children, and helping parents to provide age-appropriate explanations and interventions as well as helping parents not to blame themselves for factors over which they apparently have little control.

Behaviour and emotions in general (internalising / externalising behaviour, positive and negative talk, being open or private)

In the asthma group, it was evident that the level to which the disease was controllable influenced both child and parent adjustment. In Appendix 4.11 on page 70, Schematic Diagram 5 (mostly based on the experience of A_5, with features consistent with the experience of A_4 and A_6) shows how parents' perception of limited medication effectiveness led to difficulties for the child in engaging in active sports, with the child's frustration (associated with internalising behaviours) being amplified by his being 'sporty', his desire to be 'normal' and perceiving that friends thought he should engage in active sports.

The difficulty for the parent here is that they need to make judgements about the priority for the child – developmental needs or health needs. Whichever priority and related actions are emphasised, the parent feels guilty and uncertain about not giving priority to the other need; this is likely to negatively impact on parental adjustment. Thus, this is another insight that helps to answer the question about the significance of the nature of the child's illness. Findings show that the child's symptom controllability, individual preferences, peer norms about expectations of 'normality' and the child's internalising or externalising behaviour influence parental adjustment. These factors contribute to the difficult decisions parents need to make in judging priorities. Parents may benefit particularly from support in making such difficult decisions, so that the decision-making is shared, rather than felt as an individual burden. This example is specific to the asthma group because it relates to restrictions of physical activity (which is not normally the case for children in the diabetes group), and helps to answer the question posed earlier about the extent to which illness-specific differences influence adjustment.

However, there was a common experience in both disease groups in that parents nearly always discussed what they believed to be the causes of the child's internalising or externalising behaviour. In Appendix 4.12 on page 71, Schematic Diagram 6a shows the range of causes that parents proposed for why their child exhibited such behaviour. The overlapping circles illustrate that there is a range of parents' beliefs about the causes and controllability of the child's behaviour that are often several in number. In Appendix 4.12 on page 72, Schematic Diagram 6b shows the consequences for such beliefs in the parents' actions, the results of such actions and the parents' evaluation of why the outcome for the child was effective or not.

As an illustration of how this diagram demonstrates this process, the child of D_14 demonstrated a high degree of externalising behaviour. The parents attributed the behaviour to the child's 'stubborn' personality, young age, poor 'bonding' to the mother in infancy, the child's inability to accept the illness (but parents were also ambivalent about this) and a biological tendency to have poor blood glucose control. It should be noted that all of these factors were not apparently controllable. The parents sought support through CAMHS, but believed the staff were intrusive, inappropriate and ineffective and therefore only went to one meeting, which probably added to their feelings of lack of control. (Follow the turquoise arrows on Diagram 6b in this case). Their child's externalising behaviour was just beginning to recede, which they attributed to the child getting older and more mature (again, not something they could control).

At the other end of the scale, the child of D_1 had originally demonstrated oppositional behaviour when confronted with needles at clinic and at home. The parent believed this behaviour could eventually be overcome with child and family effort and external support. She sought and received the help of the play specialist, nurses and clinic psychologist, and also praised the child's and sibling's efforts to overcome the problem behaviour. The parent reported that the child's behaviour was now much improved, and attributed this to her personal efforts, the family's and child's efforts as well as the professional support. This mother expressed pride and positive feelings about her child's progress. It is argued that the outcome for the parent in examples like this is more likely to be positive for parental adjustment.

This discussion also addresses the question about how the child's response to the illness relates to parents' adjustment. In particular, it indicates that the parents' beliefs about the causes of the child's behaviour and their attributions about child behaviour change can influence their own feelings of control. The parents' observation of whether or not the behaviour improves either reinforces or changes initial attributions, contributing to low or high self-efficacy. In terms of the impact of parental adjustment, it is likely that low self-efficacy would be associated with more poor adjustment, and vice versa.

The questions about how parents perceive their child's responses to the illness and how this in turn relates to parents' adjustment are further addressed when considering the child's negative and positive talk. In Appendix 4.13 on page 73, Schematic Diagram 7 shows that in both illness groups, there were individual differences in whether or not parents saw the child's 'negative talk' as being therapeutic for the child, and was a good coping strategy (and therefore positive) or reflective of deeper, underlying problems (such as depression), and

therefore negative. Mothers and fathers in the same families did not necessarily view the behaviour in the same way, as in the example of A_8, where the mother viewed it negatively and the father positively. The outcome for parent adjustment (as was illustrated with these participants) was that the mother found her child's negative talk more upsetting than did the father, in part because they attributed different meanings to it and felt differently about their personal responsibility for it. It was interesting that no parents viewed positive talk in a negative way, although one parent felt 'bad' about feeling negative when her child was so positive. These findings again emphasise that parents' attributions of the meaning of their child's behaviour are important for parent adjustment.

With regard to the child's behaviour of 'being open' or 'being private', a similar issue was identified in both Appendix 4.14 (Schematic Diagram 8) and Appendix 4.11 (Schematic Diagram 5). These diagrams show that parents are faced with decisions about which aspects of a child's need should have priority – health or developmental needs? Again, these issues were not disease-specific since both asthmatic and diabetic children could experience health risks by not being open (e.g. not carrying out treatment in public), and parents from both groups regarded this as being important. This emphasises that this tension and uncertainty in decision making, coupled with guilt may be a significant stressor for parents, and therefore for their adjustment. Interventions with peer groups and others to make the treatment less socially unacceptable may be worth pursuing.

Effect on child's social life

When viewing the diagrams in Appendices 4.15 and 4.16 on pages 75 and 76, it becomes clear that both controllable and uncontrollable factors influence children's ability to engage in social activities. Whilst parents do indeed need to weigh up many factors when deciding whether to allow their child to take part in activities that may carry a health risk, some factors are less easy or not possible for them to influence. Where these limitations lead to restrictions in the child's social life and to child upset, parents often also feel distressed. Some of these are disease-specific issues; for example, some asthmatic children could not go places where allergens could trigger an attack, whilst the need for a responsible adult to give injections to diabetic children was a disease-specific obstacle reported. When considering the question about the extent to which disease-specific and individual differences influence child and parental adjustment, it is apparent that the extent of such disease-specific factors over which parents have little or no control can significantly limit the child's social life, with associated child and parent upset, disappointment and sadness.

Also in connection with this question, Diagram 9a illustrates the importance of individual differences in judgements about risk; for example, parents who are more anxious and don't trust others are less likely to allow their child to undertake activities they consider to be too risky. It is interesting to note that the same issue identified in Diagrams 5 and 8 is also apparent here, i.e. the frequent difficulties parents face in making judgements about different priorities and risks. There are also situations when the parent's assessment is that the activity is safe for the child, but others responsible for the activity disagree or won't take the responsibility. These two types of experiences can be equally frustrating and upsetting for the child and parents.

In Appendix 4.16 on page 76, Schematic Diagram 9b shows the interactive relationship between the factors influencing the nature, quality and frequency of the child's social activities, the experience of the child, and the response of the parent. Where children's experiences were more restricted, parents experienced more frustration, upset and / or guilt. Furthermore, where parents' own judgements are influenced by factors such as their own anxiety and limited trust of others, it is suggested that these emotions may be particularly acute. This is because they may feel personally responsible for their child's restricted activities.

Key insights relevant to the theoretical model

On the basis of the above discussion, it is proposed that the following key insights should be included in the final theoretical model. It will be important to note if these same points arise during the analysis of future chapters, whether there are different aspects to these points and also whether there are any contradictions.

Parents' understanding of adjustment

- Parents conceptualise their child's adjustment as how adaptive they are in situation-specific as well as in general contexts, and as temporary or more enduring states;
- Parents believe that many person-specific factors affect their child's coping and adjustment, such as the child's age / developmental stage, temperament, preferences, fears (e.g. of needle-related procedures) and their own ability to cope with stressful situations;
- Parents believe that 'external' factors also affect child coping and adjustment, such as repeated hospitalisations (especially at a young age) and medication effectiveness.

- This factor, degree of medication effectiveness, was considered by parents in the asthma group to be very important, as it affected children's social lives, especially engagement in sport.

Parents' responses to child's challenging behaviour

- Parents actively attempt to find causes for the child's behaviour, and take actions consistent with these attributions (e.g. not controllable cause(s), don't try to change it, etc.).
- Parents then observe the consequences of their interventions (or non-interventions) and judge whether the interventions were successful or not in changing the child's behaviour, with parents' self-efficacy (and sometimes self-blame) being affected by the behavioural outcome.
- Parents vary in their interpretation of the meaning of some specific child behaviours, even within parents of the same family; negative or pessimistic interpretations are associated with greater parental distress.
- Parents may need help to interpret and appreciate the significance of their child's behaviour; this may reduce parental self-blame and promote more positive attributions of child behaviour.

Challenges for parents in decision-making / making judgements

- In the asthma group only, parents sometimes have to make difficult judgements about priorities (health or development) such as whether to allow their child to do active sports, knowing it will make them ill.
- A similar decision-making challenge applies to parents in both illness groups, about whether to encourage the child to be open or private (with some children preferring the latter, to appear more 'normal', but which may increase health risks)
- These decisions were a source of stress for many parents as they were usually taken independently (and whichever choice was made, arguments could be made for the alternative), and parents may benefit from specific help to share decision-making with professionals.
- Individual differences in parents' judgements of risk can have differing outcomes for the child's social life; parents' evaluation of the outcomes has implications for parental adjustment.

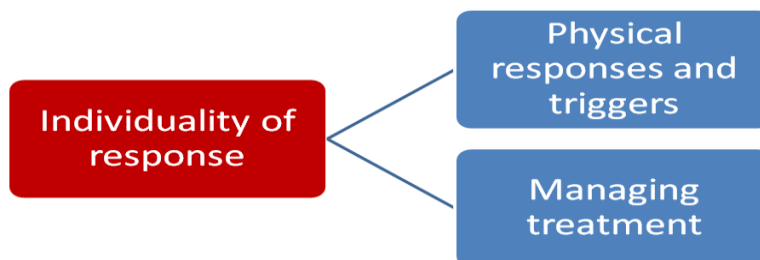
CHAPTER 5: PARENT PERCEPTIONS OF THE CHILD'S PHYSICAL RESPONSES AND TREATMENT MANAGEMENT

5.1 INTRODUCTION

This Chapter will present and analyse results of the final sub-theme of 'Individuality of Response' introduced in the last Chapter. However, this Chapter has a focus that is tangential to that of Chapter 4, in that it relates specifically to the child's general physical responses and illness episode triggers (often perceived as individual to the child) and to managing the child's treatment. As such, it provides a conceptual bridge between Chapters 4 and 6, with Chapter 4 incorporating the concepts of individuality of response with reference to the child's emotional and social life, and Chapter 6 focusing on treatment management (although only in the context of specific episodes).

As in the previous chapter, the results of the asthma group and then the diabetes group will be reported and discussed. Following the presentation and analysis of each group's results, there will be a summary relating to each sub-theme. The Chapter will end with a cross-group comparison, and overall summary of the sub-themes and any further additions to the developing theory.

Individuality of response:

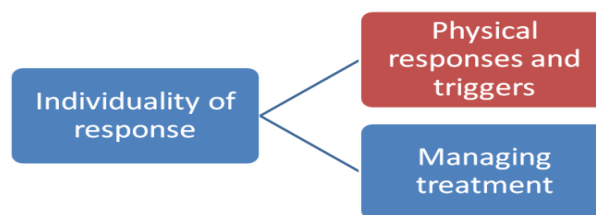


These two remaining sub-themes of 'Individuality of Response' were coded as such because during interviews, parents frequently discussed how one or more aspects of their child's unique biological or psychological makeup, or their child's age influenced how they responded physically to external and internal stimuli – either negatively or positively influencing their illness response. Similarly, parents frequently discussed how their child's

unique biological or psychological makeup or factors relating to their age either facilitated or were detrimental to optimal treatment management.

These sub-themes are potentially important for parental adjustment. If parents perceive that their child's biological or psychological makeup is a negative influence and is unalterable, then they may feel less able to influence their child's illness course or manage symptoms; this may contribute to parental stress, and influence their adjustment negatively. Equally, the reverse may be true. Some parents viewed such individual responses as temporary (for example, a child's temporary 'difficult' adolescence), which therefore might have a less negative impact on parental adjustment in the longer term.

5.2 CHILD INDIVIDUALITY OF RESPONSE: PHYSICAL RESPONSES AND TRIGGERS – ASTHMA GROUP



All parents in the asthma group discussed aspects of this sub-theme, which includes a range of areas. Further information may be found in Appendix 5.1. A significant topic discussed by parents was the type of triggers for their child's asthmatic attack or worsening symptoms (such as cold, pollen, exercise and certain foods), and whether or not these were known to the parents, therefore enabling them to be avoided.

A second topic was whether symptoms signalling an impending attack or drug side effects were recognised or not by the child, parent or both; the ability to recognise an impending attack would enable parents or the child to take early preventive action and better control symptoms. Also, parents demonstrated knowledge of drug side effects, which in some cases led to interventions to alter drugs or dosages. Further, parents discussed whether or not they felt their child's symptoms or disease course was always, sometimes or not predictable.

Finally, parents discussed whether or not their child's medication was effective or not in relieving or preventing symptoms. This topic has particular relevance to treatment compliance issues and also child and parent adjustment, as will be discussed later.

Physical responses and triggers: Examples of knowing or not knowing triggers

Nine of the parents reported that they knew the triggers for their child’s asthma attacks (A_1, A_2, A_4, A_5, A_9, A_10, A_11, A_14 and A_16). However, 6 parents reported that they did not always know the reasons for these attacks (A_3, A_6, A_7, A_8, A_12 and A_15), and one only sometimes knew the cause of eczema flare ups (A_11). (Eczema is a skin condition often associated with asthma). Further information is provided in Appendix 5.1.

Parents reported a range of different triggers, and this impacted on a number of illness-related features, for example whether or not they had ‘asthma-free’ periods in the year. For example, the following participant reported that asthma symptoms were mainly related to seasonal changes, so her child was better during the summer period.

Respondent	Interview Excerpt
<p>A_1</p> <p>Triggers usually known</p>	<p>M: It’s [asthma’s] pretty good now, actually. Although I’ve got to admit, this is like October, and he was ill last October and the October before, so...</p> <p>I: He’s generally better in the summer is he, on the whole?</p> <p>M: Yeah. He has been quite well this summer. The cough did actually go away.</p>

Other parents such as the following participant indicated that their child’s asthma was triggered by cold, exercise or singing, but not allergies, and was not seasonally-related.

Respondent	Interview Excerpt
<p>A_4</p> <p>Triggers usually known</p>	<p>I: So what triggers your asthma is...?</p> <p>M: It’s not allergies, but cigarettes will make her feel quite (makes vomiting noise).</p> <p>I: You get it when you get a bit of a cold, perhaps that triggers it a bit more, or whatever?</p> <p>Child: It can do.</p> <p>M: And doing exercise or singing all triggers it.</p>

It is likely that parents' ability to predict triggers offers them a greater ability to prevent, or at least anticipate the onset of symptoms of an attack. For example, knowing that exercise triggers their asthma may lead a child to take a preventive inhaler prior to sports and reliever with them. Similarly, knowing the degree of symptoms likely to be experienced by exposure to a trigger could affect parents' preventive (or responsive) actions. In the following example, animal dander was somewhat of a trigger, but not the main one and this affected the mother's decision-making about allowing her child to play with a dog.

Respondent	Interview Excerpt
A_2 Triggers usually known – symptoms vary with trigger	M: It's like, he was laying on the floor the other day, and the dog was up close to him, and she [grandmother] said, 'Get him off the floor. Get him off the floor.' I said, 'No, leave him to do it'. I said, 'Because if he gets himself wheezy, I've got his inhaler here'. And I said, 'It's not as if he'll...he's never had a major asthma attack when with the dog'. I said, 'She isn't a real trigger for him. You know, it could make him a bit short'. I said, 'No, just let him get on with it. He's happy enough playing'.

An interesting implication in the context of the above findings for future research is that researchers assessing psychological measures of children's and parents' adjustment or quality of life should note whether there are items that specifically and exclusively refer to exposure to allergens, exercise, cold or the impact of the seasons, as children vary in what triggers their asthma and also in how much of an impact a particular trigger is relative to other triggers on their asthma symptoms, as indicated in A_2 above.

In contrast to the preceding examples, other parents experienced some degree of uncertainty at times with regard to the cause of their child's attacks, as illustrated in the following example of a child whose parent had not discovered many of the triggers for her child's asthma.

Respondent	Interview Excerpt
A_15 Not knowing triggers	I: So did something particular trigger his asthma? Or was it just colds or something? M: They did a whole bunch of tests and they thought that it was food allergies, and they tested that. And then I mean, I'm quite sinusy, and he's allergic to grass and pollen and house mites. But that's just a sinus thing. I mean they've done, quite a few times, they've done full tests. And it was just, do you know, they reckon it was hereditary, it was just his time. But I mean I could never find the trigger, because you know, sometimes it would be at school and you'd think, 'OK, it's because he's running around' and then other times it would be at home, and other times it'd be... there was just no set reason for it happening. We tried other different food things, just in case. I mean, no cheese and the skimmed milk, but it didn't make a blind bit of difference.

Although parents did not often discuss how they felt about not knowing triggers to help them predict asthma attacks, it is likely that this could be a source of stress; not knowing the triggers for their child's asthma would mean it would be harder to predict the onset of an attack or to avoid attacks. In the case of the parent in the above excerpt, her efforts to problem-solve (for example, trying different foods) ultimately failed, which could lead to feelings of helplessness.

Similar to the point made earlier in this section, it is important to recognise that children and their parents might not know the triggers to their child's asthma, so researchers investigating treatment compliance or concordance should recognise this. For example, researchers should not assume that parents know triggers, and may need to consider including questions about parents' understanding of the nature of their child's triggers, before asking about whether they avoid them. A similar argument could be made about health promotion interventions with asthmatic children and their families.

Physical responses and triggers: Predicting and recognising signs of an impending attack or worsening asthma

Some parents reported that the impending signs and symptoms experienced prior to or at the start of an attack, or in relation to the disease course were sometimes able to be predicted (A_2, A_6, A_8, A_9, A_10 and A_15), with only one parent (one of the non-clinic participants) saying they were always predicted (A_14). Four parents said their child's symptoms and / or disease course were difficult to predict (A_1, A_3, A_5 and A_12), and one parent said this was the case for her child's eczema (A_16).

In addition, the ability to identify signs of an impending attack (or the start of an attack) is important skill for parents, as this can enable them to avoid their child having a serious or worsening attack (often requiring hospital admissions). Most parents showed significant skills in this area, discussing specifically how they identified these symptoms (A_1, A_2, A_4, A_5, A_6, A_7, A_8, A_10, A_12, A_14, A_15 and A_16). This is illustrated in the following example:

Respondent	Interview Excerpt
<p>A_8</p> <p>Recognising signs of an impending attack</p>	<p>F: Well, I was just saying that we're very sensitive to the signs of what hasn't necessarily happened yet, but what might.</p> <p>M: Yes, because we can recognise the sound of his voice when it's a bit breathy, we can see this sucking in, because when he was very little you could hear it. We'd hear a lot of wheezing. Well, as he gets older, you don't hear anything. You can just see that he's just slightly taut, and you can hear it in his voice. We often, even now, will say to him, 'Are you wheezy?' And he'll say, 'I don't think so'. And then a short while later, he'll say, 'Actually, I think I might be.' And we'll say, 'Go and do a peak flow'. And then he can't even blow in the peak flow. It's just getting higher and higher in his chest, and he's getting used to that sort of breathing in a small space.</p>

Less usually, parents had some difficulty in recognising early signs of an attack or worsening asthma. It appeared that this occurred when asthma attacks were unusual and unexpected, or where the symptoms were thought to possibly relate to a different reason than asthma (A_3, A_7). In the following example, worsening asthma was not recognised because the child and parent had 'gotten used to the symptoms' and because of a perception of what was 'normal' for asthmatic children. The parent felt that this limitation led to her child having a severe asthma attack, about which she felt very guilty at the time.

Respondent	Interview Excerpt
<p>A_9</p> <p>Difficulty with recognising worsening asthma</p>	<p>M: But he was hospitalised for a week, now let me get the year right, I think he was about to be 8, and he's now 10, so it was just over 2 years ago. And he was very, very bad then, and I think that had been building up over the years. I had become used to him having asthma, and accepting that he wheezed quite a lot, and needed Ventolin quite often, and we carried it everywhere, and it was very frequently triggered. And although he was also on steroids, it was probably too low a dosage of steroids, and with hindsight I think I was thinking, 'This is asthma. This is how it has to be. This is how [child's name's] life is going to be'</p> <p><i>Later, the respondent said:</i></p> <p>M: And the doctor then sent me up to the hospital, and I didn't get sent to have allergy tests, I got sent to the Respiratory Clinic. And that was the first time anyone had ever said to me, 'I think the Respiratory Clinic would be a really good idea for you and your son'. And I think I should have been up there years before. I really, really do. So I slightly blame the GPs. I didn't even know about it. You know, I think they should have done something earlier. I should have actually said, 'Is there no more that can be done?' Because we were sent to an eczema clinic, way back down the line, which was fantastic and we did the wet wrapping, and his eczema really, really improved. But nobody said, 'You should be getting to an asthma clinic as well'.</p>

	<p>So I felt more supported once we got there, and we went quite often to begin with, but it didn't stop him having to go to hospital. It still didn't really tip the balance between me thinking, 'You know, he's always going to be having a fairly low level of life and the steroids will just about contain it', but still didn't sort of manage it properly. And so he spilled over into this massive, terrible asthma attack, when he really was on the point of death I think, probably. And they almost put him in intensive care. He couldn't speak or walk, his asthma was so bad.</p> <p>And the doctors had a really big go at us in hospital. They really came down quite hard on us, a) for not having taken him in sooner, and b) for the fact that his asthma wasn't really under control. And I think they were right. I think I had become, I just accepted that that's what asthma was. But I do think if someone had sat me down earlier, and talked me through things, and explained a bit better, how well steroids could control asthma, how the risks are really not that great, and the risks of not taking asthma, the right asthma drugs are greater, you know I think he wouldn't have ended up in hospital when he did. We wouldn't have put him through that big risk.</p> <p>I: So it sounds a bit like you felt partly you were to blame...</p> <p>M: Yes, I did. I felt guilty. I did feel guilty.</p>
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Physical responses or triggers: Effectiveness or not of medications

Many parents discussed how the degree of asthma control was affected by the effectiveness of the medications. Only one parent (a non-clinic respondent) said her child's medication always was fully effective in stopping asthma symptoms (A_14), with 8 parents saying medication was sometimes or usually effective (A_1, A_2, A_5, A_6, A_8, A_9, A_15 and A_16). Other parents did not specifically discuss medication effectiveness in the interviews.

The following excerpt shows both situations. At the beginning, medication effectiveness was poor, which was evidently a source of some stress for this parent. However, later the medication was altered, which improved her child's health and led to the parent being more relaxed.

Respondent	Interview Excerpt
<p>A_6</p> <p>Changes in perceived effectiveness of medications over time</p>	<p>I: So how did you feel at that point, when things started to get worse, and less easy to control?</p> <p>M: A bit panicky I think, because every thing that we seemed to do, take one step and be told that this medication will make things better and it didn't. And then we were sort of going another step on, and at that point they started looking into was it just asthma or was it something else going on as well, which it turned out not to be. It's just asthma. But also tired, because she was often up, needed nebulisers during the night, and with three other ones and working as well, it was exhausting. So yes, it was quite a difficult bit.</p> <p>I: So it sounds like it was quite a difficult time with the night time waking.</p> <p>M: Yes.</p> <p>I: She woke up quite a few times during the night?</p> <p>M: She did, yeah. At its worst, she would need three nebulisers during the night. And also there's the worry that is she, during an attack, going to need to go into hospital. So you're constantly thinking about child care for the other three, because especially being on my own, you know, in the back of your head you're thinking, 'Do I need to start thinking about if I need to take her in, what can I do with these three?' And you know, that sort of thing.</p> <p>I: Hmm. Hmm. How do you generally feel now, with the situation with [child's name]?</p> <p>M: She's now kind of gone through that phase. She had a turning point I guess about a year ago now, where she was started on some new drugs, which seem to have helped her a lot. And we do things, we've had, she's been off the steroids now for three months, having been on them for two years. And now I can see an improvement in her, it kind of feels like she is growing out of it a bit, which is what lots of people always said she might do. So it's kind of nice that that's now happening, and she hadn't had a really bad attack for that year, so it's nice. It's a relief.</p>

The above excerpt highlights the importance in a parents' experience of their child's unique set of symptoms and drug responsiveness. The psychological literature on non-compliance / non-adherence has not generally recognised that at least in some cases, children and parents are very compliant with treatment advice, yet continue to experience significant symptoms. The notion of disease severity, as discussed in the literature review of this thesis, is less helpful in this context, which may in part account for why research findings are equivocal on the impact of disease severity. For example, the disease severity of child A_6 above did not change during the period referred to above (about 1 year), yet she experienced a significant

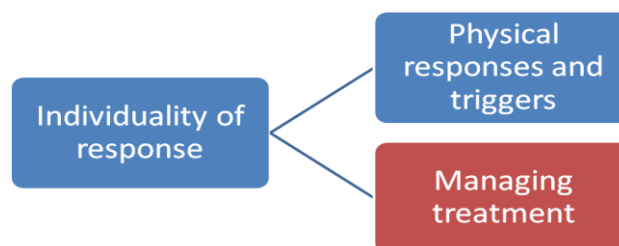
improvement in symptoms without any change in compliance with treatment. This was associated with a corresponding reduction in the parent's stress levels and impact on her family life.

5.2.1. Summary of physical responses and triggers and parent responses

The parents described a range of asthma triggers, symptoms, drug effects, and their associated behaviours and feelings. Common concepts across all these content areas are child individual differences, predictability and parental knowledge and skills of predicting and recognising triggers and identifying signs of an impending attack or worsening asthma. In addition, parents reported individual differences in their child's responsiveness to asthma medication. All of these are likely to be important to parental adjustment because they affect the parents' ability to predict and control their child's asthma and prevent attacks or worsening symptoms. Effective coping and self-efficacy are likely to be facilitated where parents' actions result in better control of their child's illness.

In common with the other sub-themes of 'Individuality of Response' discussed in the previous chapter, parents saw their child as unique in terms of what triggered asthma symptoms (and to what degree), what symptoms they exhibited (and sometimes how these changed with age) and how responsive they were to asthma drugs.

5.3 CHILD INDIVIDUALITY OF RESPONSE: MANAGING TREATMENT – ASTHMA GROUP



This sub-theme relates to how children and their parents managed the child's treatment, which consisted of taking asthma medication (such as inhalers to prevent attacks and relieve attacks) and also sometimes nebulisers, which provide medication delivered from a chamber through humidified compressed air or oxygen to a mask the child wears. Some participants said their

child was advised to additionally measure peak flows (to assess lung function), keeping a diary record of the findings. The avoidance of triggers and taking exercise, which are associated treatment management behaviours have been discussed previously (Section 4.3.3. of Chapter 4). Further information about this sub-theme may be found in Appendices 5.2 and 5.3.

Key aspects of this sub-theme are the degree of responsibility for management that the child and parent undertook and the extent of child cooperativeness. In some cases, parents took complete responsibility. In other cases, the management was shared to some extent (with varying degrees of children’s reliability) and in a few cases, the child took full responsibility (again, with varying degrees of effectiveness). Children also varied in terms of how well they cooperated with their treatment management (and consequently how much effort parents had to expend to monitor or persuade their child to manage their treatment). Finally, sometimes parents were unsure when and how much medication to give, which made treatment management more challenging.

The participants were analysed separately in two groups according to child age (8 years and under, and over 8 years). This is because age was likely to be a significant factor in regards to the degree of responsibility a child was likely to undertake and also their likely cooperativeness.

The age of 8 was chosen as a cut-off point, as this is a typical age when children start taking some responsibility for their treatment. The following two excerpts are from interviews with a paediatric asthma nurse and paediatric diabetes nurse. The asthma nurse indicated that children start taking responsibility during primary school, as they need to keep inhalers with them that they could self-administer. However, full responsibility might not be attained until 12-13 years. The excerpt from the diabetes nurse indicates 8 is an approximate age when children start taking responsibility for their treatment.

Respondent	Interview extract
<p>NA_1 Paediatric asthma nurse</p>	<p><i>This asthma nurse did not state a specific age when most children could manage their own inhalers, although she indicated that in primary school, children should have their inhalers with them, and that simple inhaler devices were used to facilitate self-administration, rather than the metred dose inhalers (MDIs) which are harder for a child to self-administer during an attack:</i></p>

<p>Age of readiness to take responsibility for treatment</p>	<p>N: We do try (once they get to be older children) we do try and give them different types of inhalers which do a similar thing - that they can keep in their pockets.....</p> <p><i>Later, she indicates that full responsibility will often be undertaken by age 12 or 13:</i></p> <p>I: So do you find parents find that quite difficult, to hand over responsibility to the child?</p> <p>N: Yes, especially there tends to be the one that has a lot of problems, and they <i>know</i> that if they don't take their medication, they become quite <i>unwell</i>. And even when we try and make the regimes very very simple, so that that they might only be taking one or two medications in the morning and one or two in the evening, just to try and make it simple so it's less likely for the child to forget in that transition period, how much do the parents say to the 12 or 13 year old, 'Well now it's <i>your</i> responsibility'. It's trying to get that transition right. Parents I think feel that they're nagging, saying, 'Have you taken it today?', (laughs) rather than being there, just giving it to their child, child takes its puff, and they're off. It's sort of like anything – the parent letting go, but knowing that this could actually have quite serious consequences if the child doesn't... I think that's quite hard sometimes.</p>
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Although the following extract was from an interview of a paediatric diabetes nurse (i.e. it is a different health condition), it is likely that children will be developmentally ready to take some responsibility at similar ages for both conditions.

Respondent	Interview extract
<p>ND_1 Paediatric diabetes nurse</p> <p>Developmental readiness for taking some responsibility</p>	<p>I: To what extent do you feel the children take responsibility for the management of their care?</p> <p>N: (pause) I think a lot of children take responsibility, often around the age of 7, 8, 9, that kind of age. They suddenly start maybe saying, 'Well, perhaps I could do an injection myself', or.. and if they're diagnosed at that age, then we try and encourage them to do it right from Day One. A lot of mothers feel that they don't want to give that away. Like that's their thing, their control, their way of helping and managing their child, and a lot of parents find it quite hard to let their child start doing their own care. So I think a lot of what influences it is from the parents and how they feel about...about helping their child and so on. And also what they worry, that you know, 'Oh, if my child does it, they might not get all the insulin', or 'Can I let my child do a blood test at school without me seeing the result', or.. Starting to give responsibility away to the child is quite a scary thing for a lot of parents.</p>

Individuality of response: Treatment management - children aged 8 and under and those over 8 years

Six children in this sample fell into the younger age group (2-8 years), and ten in the older group (10-16 years). The children's degree of cooperativeness, participation and reliability in treatment management varied. Where the child cooperates with treatment, and reliably indicates their need for medication, it seems likely that parents will not find treatment management as stressful as they would with an uncooperative child. Although parents in this sample did not explicitly report that they felt their child's cooperation and reliable participation in treatment management led to them feeling more relaxed than otherwise, they did make positive comments about their child's participation and growing responsibility (for example A_2 and A_16). It was more typical for parents with children who took less responsibility to report finding this aspect of life stressful.

On the basis of parents' descriptions of children's cooperation, participation and reliability in treatment management, the participant responses were grouped as follows (and described in more detail in Appendices 5.2 and 5.3):

- *Parent control of treatment management:* The parent controls all treatment routines and makes all decisions about when medication is given. The child is cooperative.
- *Limited shared control:* The parent controls the routine, but the child sometimes indicates when medication is needed and sometimes participates in self-medication, although cooperation may be variable. Where the parent expects the child to take medication independently (i.e. children over 8 years), the parent lacks confidence that the child has done this and they need frequent reminders. The parent has to check that sufficient medication is available.
- *Some shared control:* Parent controls the routine, but the child normally takes medication and normally indicates when medication is needed. They are cooperative in general. Where the parent expects the child to take medication independently (i.e. children over 8 years), the parent sometimes needs to prompt the child to take it, and the child may not take their 'preventer'.
- *Effective shared control:* Child nearly always remembers to take medication, but might need reminders. The older children (i.e. those over 8 years) take control of treatment management, but the parent may 'keep an eye' and may check the child has

taken medication. The child cooperates with treatment, and tells parent if insufficient medication is available.

The following table shows that the older children, particularly teenage girls, tended to have the most effective shared control, whilst younger children (4-5 years) and adolescent boys tended to be less cooperative and take less personal responsibility.

Table 5.1: Comparison of levels of sharing of treatment management between parents and children from two age groups – Asthma Group

Groups	Children 8 years and under	Children over 8 years
<i>Parent control of treatment management</i>	A_13 (boy aged 2 years)	None
<i>Limited shared control</i>	A_2 (boy aged 4) A_7 (girl aged 5)	A_10 (boy aged 11) A_8 (boy aged 12) A_15 (boy aged 13) A_5 (boy aged 15)
<i>Some shared control</i>	A_16 (boy aged 4) A_11 (boy aged 7)	A_1 (boy aged 10) A_9 (boy aged 10) A_14 (girl aged 16)
<i>Effective shared control</i>	A_12 (boy aged 8)	A_6 (girl aged 13) A_4 (girl aged 14) A_3 (girl aged 16)

Limited shared control

This example illustrates a child from the ‘over 8’ group with ‘limited shared control’. The older and younger groups of children in this group differ in some respects. The parents of the younger children appeared to believe that their child’s limitations in participation and cooperation were developmentally-related, whereas with older children, parents believed that the child was capable of participating and cooperating more fully, but didn’t for some reason:

Respondent	Interview Excerpt
<p>A_15</p> <p>Adolescent boy</p> <p>Limited shared control</p> <p>Child does not take full responsibility for treatment</p>	<p>M: You know, he doesn't take his medicine like he should, you know, and if he did, he wouldn't get wheezy. I believe he wouldn't get wheezy. It would happen occasionally, but not to the extent that it does now. But he's one of these kids that, and I'm the same really, if it's not broken, don't fix it kind of thing. I mean, when you're healthy, you don't think to take it. But he's quite responsible and if he is starting to get wheezy, he'll stop and he'll take his medicine if he's got it. But he'll not push himself, he'll wait until he....</p> <p>I: So, he takes a preventer every day, or...?</p> <p>M: Yes, he takes his Singulair and he takes Serovent, and then he's got, he used to take Ventolin, but because he wasn't taking his medicine regularly, they've given him, I can't remember what they've given him, but it's got all the stuff of Ventolin, but it's got cortisone in there, so it'll be a preventer as well as just a fixer or whatever it is. So, we're hoping that that will then at least get something into his system.</p> <p><i>Mother and grandmother discuss why child / grandchild doesn't take his medicine, and their own actions.....</i></p> <p>I: So, how do you feel now, about the situation, with [child's name's] asthma?</p> <p>M: Um, yeah, I'm fine with it now, because he understands it, and he's maybe not as responsible as he could be about it, and I maybe don't nag him as much as I, in fact I don't nag him at all to take his medicine, and I know I should. But I don't 'cause I'm as much a scatterbrain as he is really. But he knows what can happen, and he's been reminded of what can happen. He's been better with his medicine since then. [serious asthma attack resulting in hospitalisation]</p> <p>G: I don't know actually. I mean I was forcing him.</p> <p>I: You were forcing him to...</p> <p>G: To take his medicine in the morning.</p> <p>I: How did you manage to persuade him to do that?</p> <p>G: It permanently sat on the table, so when he came downstairs for breakfast in the morning, it was there. I could see it, and he could see it. And if he didn't voluntarily take it, I'd say to him, 'Don't dare go upstairs without taking your medicine'. That was in the other house. Most of the time I don't even see him in the mornings here. And he's got his medicine upstairs, so I don't even know if he's taking it or not. But I did force him to take it.</p> <p>M: Maybe we should drag it downstairs again.</p> <p>I: Does he keep a record of it or not? He doesn't really record what he's taken, or not?</p>

M: No, no. It's hard enough to get him to take it, let alone record it.

Mother and grandmother discuss the impact of the recent emergency admission with an asthmatic attack....

M: So, probably a good thing in a way, because it was a scare. I think it scared him and it definitely scared me.

G: I was scared some of the time. I mean, one time I took him to the hospital, the specialist, and the [doctor's name] explained to him, when he first arrived here, the implications of him not taking his medicine as a preventative thing. You see, he seems to think if he can blow on that thing...

M: I don't even think that he doesn't want to take them. He's just like me, he forgets.

I: And on the whole, I think you said this already, but on the whole he manages himself except sometimes you need to prompt him, but you're not really sure whether he takes his things out. Does he do peak flows any more, or not really?

M: He generally only does them when he goes to the specialist. We've got a peak flow, and we will need to start doing that. I mean, when he goes to the doctor, his peak flow's OK, a lot better than it was, but it's not as good as it could be. I mean, the last time we went to his doctor, the doctor said, 'You know, you're doing this, but you could be doing this, if you'd just take your medicine'. So...

I: How does he respond to that?

M: 'Oh yeah, yeah. No, I know, I'll be better'.

I: Does it make any difference?

M: (shakes head, laughs)

I: No.

M: (laughs) But I mean he's a teenager anyway. He's as scatterbrained as much as he was before he was a teenager. There's no chance now.

I: So you're hopeful that maybe when he gets a bit older, he might take up some of these ideas?

M: Hmm.

Grandmother reflects on a recent emergency hospitalisation and what treatment management was like when grandchild was younger ...

I: He'd forgotten his medication or something? That may have been what it was, he was not keeping taking his medication?

	<p>G: Yeah, he tends not to take it, but I know he's got one in his schoolbag. But if he goes out, say he's at a friend or something, without that schoolbag, he doesn't think of putting one in his pocket.</p> <p>I: No, no.</p> <p>G: In that respect, it was easier for us to control it when he was smaller, you know. You could, the onus was on you to make sure he took his medicine. Now that he's older, and he's doing it himself, we tend to lose track a bit.</p>
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Some shared control

This next interview excerpt is an example from the '8 and under' group where there was 'some shared control'. The younger children were not expected to know when and how to take their own medication, but parents said they would report symptoms and participate to the best of their ability, considering their developmental level. The main difference between the younger and older children, as explained earlier, is that the parents of the older children expected the child to take their medication independently, although they reported that the child sometimes needed prompting.

Respondent	Interview Excerpt
<p>A_16</p> <p>Pre-school boy</p> <p>Some shared control</p> <p>Cooperation with treatment management</p> <p>Uncertainty about medication management</p>	<p>I: Do you sometimes give [child's name] his medicine or not?</p> <p>M: [Husband's name] does in the morning, and in the evening.</p> <p>I: In the evening, and you do a bit if it's needed during the day?</p> <p>M: Yeah, but [husband's name] does the puffs in the morning and in the evenings.</p> <p>C: Well, when we need a blue puff, I do the blue puff.</p> <p>I: Do you?</p> <p>M: Yes.</p> <p>I: And you're quite good at the puffs, are you?</p> <p>M: He can do it now, can't you?</p> <p>I: Very good. When did you learn how to do that?</p> <p>M: About two months ago.</p>

	<p>I: (To child) That's very good, because it's quite hard, isn't it, to know when to breathe and everything, isn't it?</p> <p>M: Yes. (to child)</p> <p>I: (To child) Quite hard, so that's very good.</p> <p>C: And it, because if sometimes Daddy doesn't know when to press, I do it!</p> <p>I: (To child) Oh, that's good then. So you help your Daddy then, that's good, that's good. (To mother) So would you say you both take the same approach in managing [child's name] asthma then? You would both agree with whatever needs to be done?</p> <p>M: Yes.</p> <p>I: So, would one of you say, 'I think he needs a puff now' and maybe [child's father's name] would say, 'No, I think we should wait', or...?</p> <p>M: Oh yeah, we do it together. But it's hard sometimes, because sometimes he doesn't know how many puffs to give.</p> <p>I: So sometimes you're not sure.</p> <p>M: Yes, you're not sure, and then we don't want you to go to the GP all the time, and you know that you can give up to ten, but you have to think, 'How many do I give now?' Like yesterday, we gave one every four hours and then we thought, 'Oh, maybe we give two'. And then I said, 'Maybe later give five'. But the thing is sometimes you're doing it in the blind.</p> <p>I: Yes, just kind of experimenting really.</p> <p>M: Yeah.</p> <p>I: To see how it works.</p> <p>M: How it works.</p>
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The parent in this interview was evidently pleased that her child wanted to participate in his treatment management and cooperated well. However, despite complying with treatment, his asthma symptoms were not well controlled, which was a concern. As indicated in the latter part of the above excerpt, this parent and her husband found it difficult not knowing the precise dosage to give their son prophylactically and when he was having symptoms. In a separate part of this interview, the parent expressed frustration that different health professionals suggested different drug dosages (numbers of puffs), which made the parent feel that she and her husband had to sort the problem out alone. This seemed to be a source of stress for this parent.

Effective shared control

The final extract is taken from the ‘over 8’ group of respondents where there was ‘effective shared control’. As mentioned earlier, only one participant from the ‘aged 8 and under’ fell into this group (A_12). This child had severe asthma, requiring very close monitoring of symptoms and a high degree of preventive intervention to achieve good control. It’s possible that this increased the child’s motivation to cooperate and his expertise in treatment management, so this degree of shared responsibility might be atypical at this age. Therefore, this grouping primarily applied to older children.

Respondent	Interview Excerpt
<p>A_6</p> <p>Adolescent girl</p> <p>Child takes responsibility for treatment</p>	<p>I: Excellent. So does [child’s name] tend to do everything herself?</p> <p>M: Yes.</p> <p>I: You don’t do anything really for her.</p> <p>M: No, she does, and I guess she’s been like that probably certainly for the last year. She does all her own tablets, all her own inhalers, and monitors all of that herself. She’ll tell me if she’s running out of stuff. Hmm.</p> <p>I: OK, and before that, was it mainly you that did that?</p> <p>M: We had a period where she would be doing it but with me prompting her all the time to do it, and reminding her, and obviously when she was younger, then it was me that did them, yeah.</p>

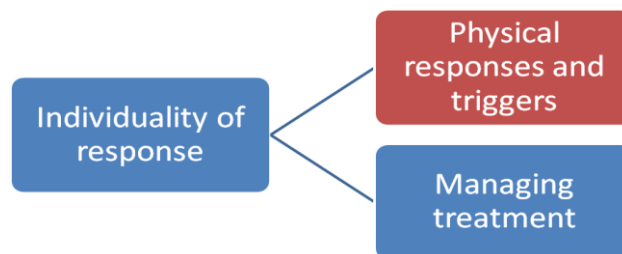
5.3.1. Summary of managing treatment and parent responses

In this sample, the younger children (under 8) were generally cooperative, although their parents took responsibility for their care; where the child was less cooperative, the parent attributed this to the child’s young age (i.e. frustration at restrictions). A source of stress seemed to be about how to choose the correct treatment dosage, as the dosage is not strictly prescribed (e.g. ‘up to 10 puffs’), and the fact that the asthma was not well controlled despite the parents’ conscientious management. Also, conflicting advice about drug dosages and other aspects of treatment management contributed to stress.

It was interesting to note that no parents of children with asthma described having an ‘asthma plan’ for their child, as recommended in the guideline by The British Thoracic Society (2009). (Asthma plans help parents to monitor the child’s progress more closely and help to make more transparent to other health professionals the treatment patterns over time, for example how many puffs of the inhaler were given in response to which symptoms, at what times and in which contexts).

The eldest children in this sample, all boys, tended to be less reliable, participative and cooperative in their self-care, and one respondent felt it was easier to manage treatment when the child was younger, as when older, they don’t supervise them as closely and ‘lose track a bit’. Additionally, ‘being a teenager’, making worse an already existing tendency to be ‘scatterbrained’, was identified as a reason for poor treatment management. The limited cooperation and degree of responsibility of this group of children was a concern for parents, who worried about the child’s future lung function and the risk of future asthma attacks.

5.4 CHILD INDIVIDUALITY OF RESPONSE: PHYSICAL RESPONSES AND TRIGGERS – DIABETES GROUP



All but two parents (D_5 and D_16) spoke about their child’s physical responses to diabetes and / or precursors to changes in their health state. The term ‘precursors’ is possibly a more accurate term for this group than ‘triggers’, which is more salient for the asthma group. Parents described a range of examples of precursors that preceded changes in their child’s blood glucose levels and related behaviours. These included time of day (as some children had a tendency to have ‘hypos’ in the early morning or late evening), entry to puberty (which led to more unstable control in some children) and insulin dosage changes. Further information about this sub-theme may be found in Appendix 5.2.

As with the asthma group, some parents were more able than others to predict the onset of changes in their child's health state. For diabetic children, this was abnormal blood glucose readings, usually of hypos. Three parents (D_9, D_14 and D_15) discussed how they sometimes didn't recognise the onset of hypos or hyps, whilst 6 parents described very particular behaviours that enabled them to predict the onset of one or other of these states (D_1, D_2, D_4, D_6, D_7, D_13); these predictors were not the same for all children, and sometimes parents described how preliminary behaviours differed between different episodes for the same child, for example some children went pale, with a glazed look, whilst others experienced early behavioural changes. Being able to recognise the onset of a 'hypo' is important, as early intervention (for example in the form of offering a sweet drink or chocolate) can prevent its progression.

Unrecognised hypos, or hypos that progressed without early intervention were described by a number of parents, and also reflected individual differences in the symptoms displayed. These seemed to be quite specific for each child, and sometimes varied at different times for the same children (as reported by D_4, D_9, D_12 and D_14).

All but 3 parents (D_5, D_15, D_16) described, usually in some detail, individual physical or psychological factors associated with their child's response to the illness in general. For example, the parent of D_2 described how her daughter's blood sugars tend to drop earlier than other similarly-aged children on a similar insulin regime; this knowledge helps her to manage the diabetes more effectively. In another example, the parent of D_10 knew that since her son was typically very active, he was at risk of hyperglycaemia when going on an aeroplane, so would need adjustment to his insulin. Therefore, parents' knowledge of their own child, and also of factors that could predict abnormal blood glucose states, enabled them to prevent the onset of problems.

Physical responses and triggers: Ability to predict onset of hypos or hyps

In this excerpt, the respondent describes how her teenage son had a tendency to have morning 'hypos', which the parent recognised he could avoid by eating something at bedtime and checking his blood sugar in the morning. This child had been diagnosed for 6 years, so the extensive experience of the parent (together with experience of other family members having diabetes) may have played a part in her accurate identification of these predictors:

Respondent	Interview Excerpt
D_7 Ability to predict hypos	<p>M: Just recently I've spoke to a teacher there, 'cause he's been playing up a bit at school, but they've noticed that he's been quite sleepy in lessons. At that's because, as I've said, he's been low in the mornings.</p> <p>....</p> <p>I: You said he sometimes has hypos, or..</p> <p>M: It's more lows - he has more lows, and they're usually in the morning...the worst time is when it happens in the morning and he has to go to school. 'Cause I am trying to get him (gestures to youngest son) ready. I know I've got to get to work, and again he's letting himself go low because the last couple of times he didn't have anything to eat before he went to bed. And if he'd have done his blood sugar - if we'd have seen it was low - that wouldn't have happened in the morning.</p>

In contrast, the following parents of D_12 discussed how their child had a problem of night-time hypos, but they had limited ability to predict when these would occur, despite the child following recommended treatment. The consequence of this was progression to a serious hypoglycaemic attack:

Respondent	Interview Excerpt
D_12 Limited ability to predict hypos	<p>M: All [child's name's] problems revolve around night time hypos, and they're very severe. So, as you can see, like you said, going off to University and things like that...</p> <p>F: Sleepovers, going to a pub and always having to have somebody there that's responsible for her. And she's seldom going to be able to relax. In this episode on Tuesday, which was so out of the blue, and she had one.</p> <p>M: It had no rhyme or reason.</p> <p>F: She had one in January last year, when she just flaked out in Tesco's for no reason, and we didn't even see it coming....</p> <p>I: She just collapsed, or..?</p> <p>F: Yeah, she collapsed with a hypo. Um, we'd been up an hour or so, she'd had her breakfast, done her readings in the morning, fine, gave her insulin, went to Tesco's and within 2 or 3 minutes of being there, she collapsed, and was fitting. (Pause, apparently trying to contain his emotions).</p> <p>I: That's upsetting isn't it, because you feel like you've done everything you should have done.</p> <p>F: Exactly. Yeah, and you think, where's it come from? And you start questioning, 'Did I give her too much insulin?'</p>

	<p>M: ‘Did I give the right insulin?’</p> <p>F: ‘What happened to cause it?’ In the end, the paramedics came out and they did a BM, and it was 4.5. And you think, ‘Well, I must be going mad! She’s had a hypo!’ [4.5 mmol/l is low normal].</p>
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The above excerpt shows that the parents of D_12 found it very concerning that they couldn’t predict when a ‘hypo’ would occur, and their preventive actions were not necessarily effective. This had repercussions in the child’s social life and parents’ feelings about the illness and its consequences. Elsewhere in the interview, these parents reported how the child’s teachers excluded her from some school trips (unless accompanied by a parent) because of her frequent unpredictable ‘hypos’. The parents said the teachers compared their child unfavourably with a classmate with diabetes who didn’t have ‘hypos’, and who was allowed on trips without a parent. The teachers however may not have appreciated that a lack of ‘hypos’ may actually indicate poor control (because the child’s blood sugar tends to ‘run high’, which is more detrimental to longer term health). Therefore, such child individual differences could contribute to child and parent social isolation.

Parents also reported specific symptoms during a full hypoglycaemic attack, which sometimes differed even in the same child. This could be alarming for parents, as they wouldn’t necessarily know what to expect during such an episode. In the following excerpt, although the parents said their child had 1-2 ‘hypos’ per week, the symptoms of each hypo were different:

Respondent	Interview Excerpt
<p>D_14</p> <p>Adolescent girl</p> <p>Hypos are all different in characteristics – no ‘typical’ hypo</p>	<p><i>Describing a recent ‘early morning’ hypo....</i></p> <p>M: This hypo, she couldn’t speak, she lost control of bodily functions, she was sick, you know, every one is completely different.</p> <p>I: So the hypos that she has are all different from each other.</p> <p>F: Yeah. But that one, at the time, your blood sugars were...</p> <p>M: They were 5.9, but I imagine that she’d been low, and then...</p> <p>F: If we said to you that somebody has a bounce...</p> <p>M: It was her own bit of insulin that - all diabetics have a little bit.</p>

As discussed in Chapter 4, the parents of D_14 also reported that their daughter's externalising behaviour was sometimes difficult to differentiate from 'true' hypos. Also, if hypos are different in character, this would increase the difficulty of differentiating 'hypos' from behaviour unrelated to fluctuations in blood sugar. Furthermore, the child's general poor compliance (e.g. passing off friends' blood sugar results as her own) may have led to parents not recognising more objective signs that a 'hypo' was the likely reason for behavioural changes.

Physical responses and triggers: Physical responses in general to diabetes

Parents often described specific biological or psychological factors that affected their child's physical responses to the disease. The most common factor (also alluded to in some of the above excerpts) was the child's tendency to experience night time or early morning 'hypos' (D_2, D_5, D_6, D_7, D_11, D_12, D_14). Others had 'hypos' at other times of the day also or mainly during the daytime (D_1, D_6, D_12). In most of these cases, including these last three examples, parents perceived that their child was compliant with treatment recommendations but still experienced these problems, which they attributed to their child's unique responses to the disease. This was illustrated in the example of D_1 in section 4.8.1 of the previous chapter, where the parent described how she perceived her son's regular hypos reflected that he was not a 'bog standard tick along nicely diabetic'.

The next most commonly reported group of physical responses related to the effects of their child's exercise or eating habits on their diabetes. This was reported by four parents (D_3, D_4, D_10 and D_14). In two cases, parents felt that exercise improved glucose control, and in one case that it led to worse control. In the latter example, the daughter wanted to lose weight but this was unsuccessful (because it led to hypos, which she counteracted by eating too many sweet things), as elaborated upon in the following excerpt:

Respondent	Interview Excerpt
<p>D_3 Adolescent girl Child's individual response from exercise on glucose control</p>	<p>M: I think that at the moment, again this is very heavily linked with her age, she is very into her personal appearance. And she wants to lose weight. She wants to lose about half a stone. Now you've just seen her, and she's quite tall and she's not thin or slim particularly, but she's not really overweight either. But I said I'd go along with her and support her if she wanted to lose half a stone. I felt that was quite a sensible amount. And try as we may, we can't do it because it's this catch 22 and I'm sure you'll understand and hopefully [child's name's] going to ask [nurse's name] a bit more about it today. When she exercises to use up calories, she gets a hypo. If she eats before she exercises, she's taking</p>

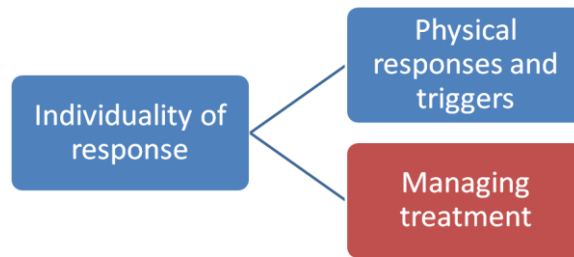
	<p>on calories that she doesn't really want because she's trying to lose weight. So it's a catch 22, whereby you're eating to get you through the activity, but you're doing the activity in the hope that you're burning calories up. So that ultimately, you're losing a pound or two in weight. And whatever she tries, however we try and manipulate it, we don't seem to get anywhere because her weight remains constant, and she has hypos. So we're into the jelly baby eating, or the Coca Cola drinking, or something, to get that sugar back up. And once you do that you're eating empty calories again.</p> <p>And that is affecting her quite a lot actually, because she is nearly 14 and you know there's a lot of girls at school that are stick thin, and inasmuch as I don't want her to get into that, I want her to know that as long as she sensibly sort of eats, I'm quite happy with her losing a bit of weight if it makes her feel good, because I do want her to feel good about herself. And I know that really does get her down at times which is a shame. And you actually feel again, her diabetes is the cause, you know. If I want to lose half a stone, I'm going to, you know, walk a few miles and eat a bit less and I'll get there. But she doesn't seem to have that opportunity at the moment. So that is affecting her.</p>
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5.4.1. Summary of physical responses and triggers and parent responses

A key aspect of this theme for these parents was their ability to predict not only when 'hypos' would occur but what the 'hypo' would be like, as for some children, the onset and symptoms were not always consistent. The consequence for the child and family were sometimes quite significant. For example, the parents of D_12 reported feelings about the effects of unpredictable 'hypos' on their child's social and school life. Furthermore, the fact that these occurred despite complying with recommended treatment may be a source of stress, because it means that parents would not be likely to have a good sense of personal control over what happens to their child. Problems with inconsistency of symptoms of 'hypos' led the parents of D_14 to feel uncertain about the predictability of their child's symptoms, and about their true nature (i.e. whether blood sugar fluctuations were the true cause of behavioural changes).

The other key aspect was about children's eating habits and exercise, and how these affect (positively or negatively) their child's diabetes control. Parents felt that knowing their child as an individual helped them to control the diabetes better. However, in one case (D_3), the parent felt that the child was not able to lose weight, despite significant efforts on both the child and parents' part. This lack of ability to control the child's weight was a source of some concern and sadness for the parent, and apparently for the child.

5.5 CHILD INDIVIDUALITY OF RESPONSE: MANAGING TREATMENT – DIABETES GROUP



For the diabetes group, this sub-theme relates to all aspects of the child's treatment management by children and their parents. All participants discussed treatment management in the interviews, often in a lot of detail. The treatment management for these children is quite extensive and more complex than for children with asthma. For all children, it involves the following:

- Following a diet high in complex carbohydrate but low in fat, and minimising consumption of simple carbohydrate (like sweets) unless 'hypo'.
- Blood glucose testing (involving pricking fingers, toes or sometimes forearm) up to 4 times daily
- Rotating sites of blood glucose testing, to avoid hardening of the skin and soft tissues.
- Insulin injections at least twice daily – if on the 'basal bolus' system (often used by older children and adolescents), they need to inject just after eating, calculating the insulin dosage based on the food intake, and may have about 4 injections per day.
- Rotating sites of insulin injections (both legs, abdomen, both arms, buttocks) to avoid the development of lipohypertrophy (which appears as lumps on the skin); if injecting into these 'lumps', the insulin injection is less effective.
- Adjusting insulin dosage based on other variables (e.g. exercise, variations from usual food intake).
- Always being prepared to respond to emergencies (particularly 'hypos') by carrying with them something sweet and taking it if they experience symptoms of a 'hypo' (if child is conscious). If the child is not alert enough to swallow safely, they can be given a highly concentrated dextrose gel orally (Glucogel / Hypostop) that is absorbed from the inside of the cheek, or if this is not possible because the child is unconscious, an injection of Glucagon ('emergency rescue') may be given.

As mentioned in Section 5.3, in relation to the asthma group, an important aspect of this sub-theme is the degree of responsibility for management that the child and parent undertake and the extent of child cooperativeness.

As with the asthma group, the data from this sub-theme were separated into two groups, where the child was 8 years old or younger, or was over 8 years, for the reasons explained in Section 5.3. Further detail may be found in Appendices 5.5 and 5.6 on pages 82 and 83.

Individuality of response: Treatment management - children aged 8 and under and over 8 years

In the diabetes group, four children were eight or younger, and the remaining 12 were aged 9-16 years. As with the asthma group, parents reported different levels of child participation, responsibility and cooperativeness; however in contrast to the asthma group, it was perhaps more difficult for children to take full responsibility for their treatment management in view of its complexity and greater number of aspects of care. In this group, no child was totally compliant and responsible with regard to all aspects of their treatment.

The interview responses on this sub-theme were grouped on the basis of parents' descriptions of children's cooperation, participation and reliability in treatment management. Three of the groups were the same as for the asthma group (but not the fourth group 'parent control' as there were no children of a very young age in the diabetes group). The description of the behaviours however related to diabetes rather than asthma management. Further details may be found in Appendices 5.5 and 5.6.

- *Limited shared control:* For the '8 and under' group, the parent assumes control of treatment, such as deciding when the child will have injections and giving these. The child sometimes takes control of *some* aspects of treatment management, but the parent has serious concerns about management. For example, the child often chooses the site (but does so inappropriately) or does blood tests but uses the same two fingers (inappropriately). Also, the parent doesn't have confidence that the child will behave responsibly (e.g. not eat sweets).

In the 'over 8' group, the children do their own injections, but sometimes needed more of them because of inappropriate eating habits. They sometimes need reminding about when insulin dosage needs adjusting, e.g. PE. They nearly always inject in the same site, and the parent often has to keep reminding the child to do the

injections. Even when reminded by parent, the child doesn't necessarily do the injection. The parent may have to constantly nag about doing blood sugars, and the child may not do enough blood sugar tests or use the same two fingers. The child eats what s/he wants, including sweets when inappropriate to do so. They don't always tell the parent about what high calorie drink or food they have had and may sometimes test friends' blood sugars so readings are normal on meter.

- *Some shared control:* For the '8 and under' group, the parent sometimes takes control of treatment, and this is generally well managed. The parent gives the injections, and normally tests blood sugars (but child sometimes does). The child will generally behave responsibly (e.g. take glucose tablet if 'hypo', take food with them when out). However, the parent may not be fully convinced that child will be truthful or cooperative regarding meals, snacks, etc.

In the 'over 8' group, children typically test their own blood sugars and inject themselves, but the parent may need to check they have done this. They are not always willing to eat, inject or do blood sugars when required. They usually rotate injection sites but might over-use them. They don't always tell or may not always be truthful about what they've eaten or injected. The parent tends to choose food at home, and child usually eats appropriately, but may eat what they like away from home. They know how to manage hypos / hypers without help.

Effective shared control: The one child in '8 and under' and those so grouped who were over 8 years show a high degree of responsibility and involvement in treatment. They typically give their own injections (sometimes under supervision), and choose injection sites but may avoid one area. They reliably take snacks with reminders and generally don't eat sweets without permission. They test their own blood sugars but might need reminding and help interpreting results. They fairly reliably tell the parent when they are unwell. The parent is confident that the child will not lie about anything to do with treatment (e.g. pretending they are 'hypo' in order to get a sweet).

The following table shows that whilst the 6-8 year olds were represented across the three groups, parents of 9-10 year olds reported the fewest concerns about treatment management, although there was one exception (D_16). (Further detail is shown in Appendices 5.5 and 5.6). This suggests that adolescence may be a particularly challenging time for both parent and child in relation to this complex treatment management regime.

Furthermore, parents take more responsibility personally when the child is younger, and although parents of adolescents sometimes feel that although they ought to give their child more responsibility, they are not necessarily able to do so confidently. Length of time since diagnosis may also be a factor affecting the child's treatment adherence, as adolescents may have had the disease for longer than the younger children in the sample; a number of parents described how their adolescent child was 'fed up' with having diabetes and this could contribute to poor treatment management.

Table 5.2: Comparison of levels of sharing of treatment management between parents and children from two age groups – Diabetes Group

Groups	Children 8 years and under	Children over 8 years
<i>Limited shared control</i>	D_15 (boy aged 8)	D_14 (girl aged 13) D_7 (boy aged 15)
<i>Some shared control</i>	D_4 (boy aged 6) D_6 (girl aged 8)	D_13 (girl aged 12) D_8 (girl aged 13) D_11 (boy aged 15) D_10 (boy aged 16) D_9 (girl aged 16)
<i>Effective shared control</i>	D_2 (girl aged 8)	D_1 (boy aged 9) D_5 (boy aged 10) D_12 (girl aged 10) D_16 (boy aged 16)

Limited shared control

Two excerpts have been selected, to illustrate 'limited shared control'; one is from the '8 and under' group (D_15) and one from the 'over 8' group (D_7). This shows how developmentally-related issues create different sources of stress for parents of younger and older children.

In both cases illustrated below the child took little responsibility, but the parent of the younger child had more control over whether her son received appropriate treatment. Whilst a key source of stress for the parent of this 8 year-old was the difficulty of persuading him to have his injection in different sites (which she felt led to more pain and bruising), a major source of stress for the parent of the 15 year-old was her son's poor self-management, which put more onus on her to intervene in treatment.

Respondent	Interview Excerpt
<p>D_15</p> <p>School aged boy</p> <p>Limited shared control</p> <p>Limited shared control of treatment, limited participation and cooperation</p>	<p><i>Mother discusses injections and blood tests:</i></p> <p>M: ... So I mean, finger testing, needles, blood tests. He's absolutely fantastic, he's so brave. He doesn't bat an eyelid. And I mean, I flinch, and people say, 'God, he's so good'. He doesn't even, because I do it so quick, it's over, no big deal it's done. It's over. Get on with it.</p> <p>I: So you do the pricks usually?</p> <p>M: Yeah. Well, he does his finger testing, but I do the injections. We're still trying to bring him round to actually injecting himself. He's not very keen on that. And to be honest, I don't think he's mentally, he hasn't grasped the importance of it. So I wouldn't feel confident that he's got it, you know, and he knows what he's doing. But yeah, so it's an ongoing thing....</p> <p>I: So he doesn't need an injection during the day, on a school day?</p> <p>M: No, no. He takes his own bloods, and if there's a problem, or if it's high or low, they phone me. And I'll talk to them, and if it's worse, I'll go down there. But I don't if I don't have to, because I think, 'No'. He needs to just get on with normal school. So, he has one in the morning, he has his dinner and I inject him after his dinner and then he has one before he goes to bed. But, you know, we manage it. But it's something else to think about.</p> <p><i>Mother discusses about rotating sites:</i></p> <p>M: We've tried recently, actually, to change because he's always had his injection in his bum. And I think that's because he doesn't see it, Mom has to do it, and I do it so quick it's just not... But he was getting lumps. So I said, 'We're going to have to move it to the leg'. But he was not happy. He screamed, and, because he could see it, he was tense and it hurt, but it was trying to get him to get his own pens so in the end, he can take control and he can do it. But I don't push the issue maybe as much as I possibly could, because I just think, 'You know, yeah, he's doing his finger testing, he could tell me if he feels funny, he knows if he's thirsty or whatever, but he doesn't like change'. It did leave bruises, and that breaks my heart, cause it's like little bruises on his little legs, and he's a skinny little thing. And I think, 'Oh no.'</p> <p>So, yeah, this is going to be the next thing, is trying to get him, 'Right, you are going to do this', to help himself. But it is like, you stab a needle into the leg and you have to hold it there and you do that three times a day, sometimes more. So, yeah, it's a big thing for him. I know it is. That's why I think he just likes it in his bum. He doesn't see it. I do it. I do move the sites around now, to prevent lumps and stuff, but....</p> <p><i>Mother discusses blood tests:</i></p> <p>M: And his finger pricking, he will not change his finger. And it's got so hard and callous and hard skin now, he's struggling to get blood. And I</p>

	<p>say, '[Child's name], you're going to have to use another finger', but he won't because of course that's going to initially hurt. But I'm going to have to get around that one and just say, 'Look, in the end it won't give a true reading because it's such so much thick skin to get through'. So he doesn't like change. He gets comfortable with this little way of doing it, and then... but I'm going to have to. All these little challenges lay ahead of me.</p> <p><i>Mother discusses about food:</i></p> <p>M: Um, we ate pretty healthily anyway. So, they [children] always had plenty of vegetables and they don't like it but they eat it, because that's what they get. And I just say, 'You know...' And [child's name], thankfully loves fruit. He's not into chocolate; he likes the odd sweet, so that's it you know, and if they give sweets out at school, for birthdays and things, they always say, they tell him to wait 'til he sees Mom, but he comes out of school, mouthful.</p>
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In addition to illustrating the different sources of stress experienced by parents of adolescents who show limited shared control, the following excerpt also highlights the parent's views about the causes of this behaviour:

Respondent	Interview Extract
<p>D_7</p> <p>Adolescent boy</p> <p>Limited shared control</p> <p>Poor participation, cooperation and reliability</p>	<p>M: Um, I don't really feel any better. Because I mean, to be honest, he doesn't help himself a lot. I'd say he doesn't look after himself. He knows he has to do his injections, but he doesn't do it at a regular time every day.</p> <p>I: So, you were saying, since the beginning, [child's name's] found it quite difficult.</p> <p>M: He's never wanted to accept it. He's never I think a lot's due to his Dad dying when he was so young and he's always had a lot of anger in him. And this is something else he's got to deal with and no, he doesn't want to. Some days it's alright, and you go for a long period where things are fine, but then, as I said, he's gone through the teenage years with it as well and they're all up in the air anyway, aren't they teenagers they are these days. But yeah, I just have to keep on nagging, you know, 'Do your blood sugars', and he does do his injection - he's never missed one - well once he did miss one - that's going back a couple of years. He just didn't care - didn't want to do it. And I think he had to prove to himself to see what happened. If he didn't do it, what would happen? And he got quite ill, and so - and he's never ever done it since then. He was just testing it, to see if he needed to do the injection. Well it turned out he did. But he has rebelled against it.</p> <p>So, but you know, there's days when he's alright, but I just feel for me it's something else I have to keep on top of, because I just can't really rely on him to do it. So.. But as the nurse said to me, he knows he's got to inject himself. If he feels hungry, he will get something to eat. But I just wish he'd make it a bit easier for me, so that I don't have to keep saying, 'Have</p>

you done your injection?’ before he goes out. Sometimes he hasn’t, so he’ll say, ‘No’, and come in. And I think, ‘Well if I didn’t ask you...’ but I want to get to the point where I don’t have to keep asking him, do you know what I mean? I know that he’s doing it, and....

I: So you just say, ‘Have you done it..’

M: Yeah, like in the morning before he goes to school, ‘Have you done your injection’, or if he’s going back out in the evening, ‘Have you done your injection?’ Nine times out of ten he might say, ‘Yeah’. There’s that odd time, ‘God, no, I forgot’. You know... So, sometimes in the morning before he’s gone to school, he’s suddenly realised he’s got to come back in and do it.

I: He doesn’t mind your doing that?

M: Oh no, I think sometimes maybe I’ve done it too much and he knows I’m like a back up, aren’t I? I think - I think he knows that. But as for doing the blood sugars, sometimes I think he wishes I’d keep quiet. He don’t like me going on about that all the time.

Mother discusses problem of doing early morning injection:

M: But yeah, he accepts he has to do it. I mean he’s still in bed now - obviously should have done it by now. Sometimes he hasn’t got up and he hasn’t done it ‘til mid-day. That’s when I have to step in and say, ‘Look, you know you should have done it by now. You know you have to do it.’ As yet he hasn’t done it.

Mother discusses why son doesn’t like doing his blood sugars tests:

I: OK. And his blood test - he does those normally once a day, or not usually, or every couple of days, or...?

M: Whenever he feels like it. He should do one at least 2, 3 times a day. He doesn’t. I think sometimes he probably does generally forget; he just doesn’t want to do it. He gets up, gets his breakfast and it’s not a routine he’s got himself into.

I: So maybe he doesn’t really adjust his insulin that much to what his blood sugars are anyway?

M: Well it’s not very often - this is why I try and get across to him the importance of doing his blood sugars, because of changing his insulin. But as I said, if he’s feeling alright anyway, he gets up - he probably don’t think to do it. He just gets his breakfast ‘cause he’s fine. It’s only ‘cause we went through this thing with him being low that we know it’s time to adjust it now.

I: So he seems to be happy to do his injection, but not so happy with his blood sugars.

M: Yeah, he knows he has to do the injections, but the blood sugars - I think he just - it only takes a minute but it’s just a pain. And I think it’s just a constant reminder that he’s got it I suppose. Having to do it. So...

	<p><i>Mother discusses rotation of injection sites:</i></p> <p>I: OK. So, what about [child's name's] injection sites, does he choose where he does his injections?</p> <p>M: Yeah. He seems to do it in the one place all the time. He finds it easier to do it in his right leg than his left, but occasionally he's done it in his stomach. They do try and get him to do it elsewhere, 'cause they warned him of the lumps and everything, and he does know that. I mean he did tell them that he is doing it on the other sites, but I only ever see him doing it in the one leg. But again, he knows if it goes all lumpy he's got to live with it. He's been told and warned about it.</p> <p><i>Mother discusses changing fingers for blood sugar tests:</i></p> <p>I: And his fingers, when he does his finger pricks, does he change fingers, or does he usually tend to use the same fingers?</p> <p>M: I don't know. I think he tends to do it.... I know when I've done him in the morning if he's been low - 'cause sometimes I've had to do two or three, I'll change it. But he says I hurt when I do it. Maybe I press, I get hold of him too hard - I don't know. But I think it tends to be - usually these (points to fingers), either the thumb or those fingers mainly.</p>
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Some shared control

The two children in the youngest group with 'some shared control' in their treatment management appeared to show signs of wanting to take part in aspects of their self-care, but could not yet be fully relied upon to cooperate and take full responsibility. The parents did not seem overly concerned about this, as they anticipated that the child would take more responsibility when older.

Some concern was shown by parents in the 'over 8' group about risks to their child's health and safety relating to imperfect adherence, coupled with their increasing independence. This next extract is an example from this age group who exhibited 'some shared control' (D_9). This child undertook significant responsibilities for her care, although she wasn't totally compliant with all aspects of treatment. The parent did not have full confidence that her daughter would carry out all aspects of recommended self-care.

Respondent	Interview Excerpt
<p>D_9</p> <p>Adolescent girl</p> <p>Effectively shared control; good participation, and reliability – limited concerns about treatment management</p>	<p><i>Parent discusses food / eating:</i></p> <p>M: I said, ‘If we both sort of try and eat what we like, but try and do it in smaller portions’, I said. ‘And we’ll try and increase the fruit and veg’. For me, the veg part was hard, but it wasn’t for [child’s name], because she can eat anything, and she’d have a bowl of vegetables as a treat, you know, just as a snack, while I couldn’t. So she was actually better, but she sort of started it herself. And then she got to school, and she wouldn’t even have crisps, or it was always a wholemeal cracker or fruit. So she just took it on, and just was away.</p> <p>I: So you didn’t really have any conflict with [child’s name] over her diet?</p> <p>M: No.</p> <p>I: How about the injections and the tests?</p> <p>M: She’s been very good with her injections, and I could never fault her on that. The only thing I used to worry about was if you’re having a sleep over, and you’re going to have a midnight snack, as [nurse’s name] would say, ‘Have your midnight snack, but take some Actrapid as extra’. I never felt she was doing that, because I don’t think at a sleepover, although it might not be your closest friends, you don’t want people to know. That’s what I did find. That used to trouble me. The one thing [child’s name] is not good at doing is blood tests.</p> <p>I: She just likes to give it herself a morning and evening injection, does she? And you are saying she’s not so keen on doing the blood tests quite so much.</p> <p>M: No. No.</p> <p>I: But she does it, like, once a day, or..?</p> <p>M: If I say, ‘Have you done it?’ she’ll always say, ‘Yes’, but I’m never 100% sure now whether she means it or not.</p> <p>I: So you don’t look at her readings?</p> <p>M: No, I’ve stopped, well actually I have done it and she’s caught me in the box. You’re feeling as though you’re reading somebody’s diary, you know, you just feel as though it’s very intrusive. And she said, ‘you’re not doing that Mom, ‘cause it’s ages since I’ve done it’.</p> <p><i>Parent discusses rotating sites:</i></p> <p>M: It’s the injection site as well, because they do get sore, they get bruises, and you get the lumps and bumps, and when you’ve got your low cut jeans and your little crop top, you don’t want people to say, ‘What’s that there?’ and things.</p>

	<p>I: What are all those lumps and things? She doesn't like using her tummy?</p> <p>M: No.</p> <p>I: So is that an issue, or not with her at the moment?</p> <p>M: I think it was at the hospital at first, again with the doctors. 'Well, you should be injecting a different place each time. You should be here and you should be here, and you should go there'. She used to come out and say, 'I'd like to see them inject themselves every day!' Mutter, mutter, mutter, mutter. So, I said to her, 'Well, do you leg first, but then go there and then there, and then do that leg and all this and all this'. And it did get to the point, and she's adamant, that she's not injecting her tummy. And sometimes when she hasn't been well, and I say, 'If we use Actrapid', I said, 'if it goes in your tummy, in goes in quicker.' And she won't, no. It's, you know, that's the stuff that's the trouble, yeah.</p> <p><i>Parent discusses child taking responsibility for self-monitoring:</i></p> <p>M: I think what it was, was [child's name] just took it in her stride. I can remember once her being at school and her phoning me up and saying her sugar levels were high. And she knew herself, and she said, 'Oh Mom, they hadn't a clue what was wrong with me'. She said, 'I know what's wrong with me, I need some Actrapid and I haven't got any'.</p> <p><i>Parent discusses child's overall degree of responsibility:</i></p> <p>I: So, does she more or less decide everything about what happens, and she doesn't need any prompting from you?</p> <p>M: No, I would say [child's name] now is pretty much in control. I still find though that she does want me when she's not feeling 100%. I know all children want their Mom, and I know she's growing up, but I think she feels better if I'm there.</p>
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Effective shared control

One interesting observation concerning the four children who apparently had 'effective shared control' was the parents' reference to their child's characteristics or personality that they felt helped them adjust better to their treatment regime. For example, the parent of D_16, whose son effectively shared care, felt that he was accepting and uncomplaining, and cheery if reminded about aspects of care:

Respondent	Interview Excerpt
<p>D_16</p> <p>Adolescent boy</p> <p>Effective shared control</p> <p>Personality or characteristics that helped good control.</p>	<p>M: But the thing is, as well, I think when it's your child, perhaps you don't give them as much credit as you should do for being responsible, because he knows it's a life threatening thing, you know, it's not a case of, 'Oh, if I forget to eat, you know, I'm going to be hungry later' or something. You know, he knows himself that he's got to look after himself.</p> <p>I: Yeah, so that's quite reassuring to you.</p> <p>M: Yeah. I mean, he's been brilliant about it from the moment... I mean he's never complained about it from the moment he was diagnosed.</p> <p>.....</p> <p>M: He just judges how he is on how he feels, and what he was [blood sugar] in the morning. And that's why I always shout after him as he's going out the door [to school], 'Don't forget...'. Yeah.</p> <p>I: How does [child's name] react to the 'Don't forget this...' or...</p> <p>M: 'Alright Mom!' (in cheery voice)</p>

Parents of one of the children in this group (D_5) believed that their child's preference for routine was because he had Asperger's Syndrome.

In this final example, the only child in this group from the '8 and under' age group again illustrates how a parent attributed good treatment management at least in part to her child's personality, intelligence and motivation; her daughter had always wanted to 'take charge' of her treatment.

Respondent	Interview Excerpt
<p>D_2</p> <p>School aged girl</p> <p>Effective shared control</p> <p>Child takes a lot of responsibility and is reliable</p>	<p>I: I mean it sounds like your daughter takes quite a lot of responsibility for her care...</p> <p>M: ...I think a child needs to be able to have some sort of understanding as to what's going on. And some children are going to let their parents sort life out for them. And my one has been a particularly independent, stropky child who's always liked to get - sort things; she's always been independent about life. And she is bright, and she has been able to take on things. And wanted to do her own injections from probably the age of 4. She wouldn't always do it, but she wanted to know if she could. So a child I think who will take hold of the insulin and say, 'I'm going to do this' is the sort of child who'll be able to cope with it. Whereas some children who can't do that might need more time to adjust to it.</p>

5.5.1. Summary of managing treatment and parent responses

These results show that parents of children in the older age groups (primarily aged 12 or over) experienced more variable levels of participation, cooperation and reliability across some treatment areas. The parents of two children reported significant problems across most of the treatment management areas. It is interesting to note that interviews of parents of these two children (D_7 and D_14) were discussed in the previous chapter in the context of their significant externalising behaviour. The parent of the child in the ‘under-8 group’ that was described as least cooperative, participative and reliable (D_15) also experienced emotional difficulties, particularly internalising behaviour. Additionally, parents found poor cooperation in treatment management stressful, although the reasons differed between parents of younger and older children.

In the two groups where there was more shared control, parents expressed positive views about their child, and often attributed this to the child’s personality (liking to be in control, liking routine).

5.6 INDIVIDUALITY OF RESPONSE – PHYSICAL RESPONSES AND TRIGGERS: COMPARISON OF ASTHMA AND DIABETES GROUPS

There were some similar issues across both groups in relation to recognising and understanding the signs of an impending attack or worsening health state. In the asthma group, this related to whether or not the parent and / or child could recognise early signs of respiratory difficulty; in the diabetes group this usually related to early recognition of the onset of a ‘hypo’. In both groups, some parents spoke very knowledgeably about this, expressing how they knew how to act to prevent the attack or worsening health state, and were able to initiate treatment interventions in time.

However, also in both groups, although some parents had the appropriate knowledge to take preventive actions, the early signs were not always recognised (because the signs varied, or because they didn’t identify them as abnormal). Some parents expressed concern, guilt or distress that they ‘didn’t see it coming’. It did not appear that length of time since diagnosis was a particularly relevant factor in enabling parents to more easily identify the onset of attacks. For example, the parent of A_15, who had been diagnosed at about the age of 2 years

and was now aged 13, was still unable to identify the triggers of her child's serious asthmatic attacks. Similarly, the parents of D_12 were not able to predict when hypos would occur, even though the child had been diagnosed 7 years previously.

A significant topic for the asthma group parents was about knowing the triggers for an attack. For the parents who knew the triggers, they could take preventive action, whereas those parents who didn't know the triggers (despite lots of investigations) were less able to do so. Some parents discussed how not being able to predict what would trigger an attack led to some degree of anxiety. There was not an equivalent issue for the diabetes group, except perhaps time of day (i.e. night time can be associated with 'hypos') or their child's response to eating or exercise. However, at least parents were aware of the effects of these factors.

Another issue that was unique to the asthma group was medication effectiveness. Some parents did not feel that their child's medication adequately controlled the asthma or was able to either prevent bad attacks or stop the child's symptoms from getting worse, leading to hospitalisation. This was clearly a source of anxiety for some parents, leading to limited self-efficacy.

Uniquely for the diabetes group was the issue of whether or not the parent and child recognised symptoms once an attack had happened. A reason for this was that for the diabetes group, some parents reported that each 'hypo' was different, which sometimes made it harder to identify. Unlike the diabetes group, parents of asthmatic children tended to report a reasonably predictable range of symptoms (e.g. wheeziness, shortness of breath, not being able to speak or walk, and so on), and they seemed to have a high degree of knowledge about their child's symptoms.

Thus, for both groups of parents there were sources of stress related to triggers / precursors and illness responses related in some way to predictability and control. For the asthma group, these tended to be most often related to the ability to recognise and avoid triggers, and whether the child's medication was effective, whereas for the diabetes group, this related to being able to recognise the onset of 'hypos' or 'hypers' and predicting the symptoms of attacks, once they had occurred.

5.7 INDIVIDUALITY OF RESPONSE – MANAGING TREATMENT: COMPARISON OF ASTHMA AND DIABETES GROUPS

Whilst both groups experienced challenges in treatment management, there are some key differences in treatment that are important to consider from a psychological and developmental viewpoint. Firstly, if children with asthma don't always take their 'preventers' each day, this may not have serious short term consequences. Also, even if advised to test their peak flows daily, few children seem to do so unless they're unwell (even if the doctor thinks this would be a good idea). Therefore, some degree of non-compliance is possible without necessarily observing immediate illness effects. In contrast, if a diabetic child omits their injections for a day, they would become very ill and would soon go into a coma. Furthermore, the treatment regime for asthmatic children is usually less onerous, consisting of taking medications (orally, or by inhalation) and possibly undertaking peak flows, whereas the diabetic children have a much more comprehensive treatment regime, which involves some painful interventions.

It is therefore not surprising that parents of diabetic children, particularly adolescents, reported more problems with cooperation, participation and reliability than did parents of asthmatic children. No diabetic child perfectly complied with recommended treatment (even if it was only in relation to avoiding or over-using certain injection sites), whereas some asthmatic children were fully compliant.

The greater number of diabetes treatments, its complexity and essential daily demands can have a significant impact on the development of a young person's identity and their ability to be independent; this could partly account for why diabetic adolescents were less compliant and reliable than adolescents with asthma.

Where there was limited shared control with adolescents from either group, parents tended to partly blame the child for non-compliance. Parents of adolescents often made the point that their child 'knew the risks' and that it was up to them to avoid them (e.g. in the case of asthma, remembering to take a 'reliever' inhaler with them, or with diabetics, avoiding over-use of injection sites). The parents seemed to feel somewhat helpless in overcoming this problem.

It is interesting to note that the children where parents reported the lowest cooperation and compliance were also those who were identified in Chapter 4 as expressing a high degree of externalising or internalising behaviours. A number of these parents reported other stressors

in the home (e.g. being a single parent, few personal friendships, family bereavements, stress in other relationships and low income), which may have contributed to treatment management difficulties.

It was interesting that in both groups, the children who appeared to show most cooperation, reliability and participation were around the age of 8 years. These children perhaps were now more able to understand their treatment and its rationale, so encouraging their participation. At the same time, the greater sharing of responsibility with their parents and greater likelihood of supervision during their daily activities may have made the treatment less of a burden for both child and parent.

In both groups, as would be expected, parents were primarily responsible for the treatment management of the youngest children (under 8 years), although where children were interested in and participated in treatment, parents were pleased and this made their task easier. Parents in both groups referred to their child's personality or characteristics as helping or hindering the child's ability to cope.

An observation was made that in the asthma group, the children who were most participative and reliable with regard to their treatment management were adolescent girls. This was not observed in the diabetes group. It is difficult to say whether this has any significance, but it's possible that the tendency for girls to mature earlier than boys in adolescence is a factor. Alternatively, parents may have higher expectations of girls in terms of taking responsibility for their treatment management. The fact that the asthma treatment is less demanding than diabetes treatment may explain why this was observed only in the asthma group. Thus, there may be an interaction between gender, age and treatment demands that is worth exploring further.

5.8 GENERAL DISCUSSION AND IMPLICATIONS FOR THEORETICAL MODEL

The discussion of the findings of this Chapter will be in the context of the particular research objective to which it relates most specifically. This is Objective 2: 'Examine similarities and differences in illness and treatment features and the illness management experiences of child and parent; consider the significance of these for the child's and parent's adjustment.' As explained in Chapter 4, the more broad objectives relating to asking questions of the data, and

discovering indicators of adjustment and its meaning for parents (Objectives 5-8) are implicit within this discussion.

Also, as was the case in Chapter 4, in preparation for the development of a coherent model of parental adjustment, relationships between different aspects of the parents' experience will be explored. Schematic Diagrams (found in Appendices 5.7-5.13) will again be used to facilitate expression of meaning and highlight influences, and these will be incorporated within the discussion of findings. As a reminder, the meanings of the various symbols, colours and directional arrows in the schematic diagrams may be found in Section 3.4.2.4 of Chapter 3. The Chapter will conclude with a summary of key insights for the theoretical model that have been gained from undertaking this process.

As in Chapter 4, questions that have arisen in the context of Objective 2 will be used to help focus the discussion. Particular questions are, 'Which features of the child's illness and illness episodes are important for parent adjustment, for example, the degree of predictability of illness episodes and hospitalisations, frequency of illness episodes, and severity of attacks?' and 'How and why do parents sometimes respond differently in similar circumstances and illness episodes, and how do these responses influence or reflect their adjustment?'

In relation to the first question about the significance of illness features, there is clear evidence that specific aspects of both illnesses influence parents' anxiety and self-efficacy. In Appendix 5.7 on page 85, Schematic Diagram 10 illustrates that the *predictability of attacks* was very important because it enabled parents to prevent them. Although this is relevant to both illness groups, difficulties in this area were somewhat more typical in the asthma group, which is why asthma has been used as the exemplar in Diagram 10. The precursors of asthma attacks were more variable, being related to any number of known and/or unknown environmental and physiological factors. Unexpected severe hypos did occur in the diabetes group, but the causes were usually later identified (i.e. due to alterations in diet, exercise and/or insulin), so errors were more likely to be corrected in future. There were a couple of exceptions to this – one of which was where the child was very non-adherent.

Parents who were unsuccessful at predicting asthma attacks (of which many resulted in hospitalisation) often expressed anxiety and concern about their child having attacks. If triggers are difficult to identify, then prevention is harder and it is more difficult to change future behaviour to alter the precursors of the attack. (Sometimes these problems led to

restrictions for the child, as reported in the previous Chapter). In contrast, parents who knew their child's triggers and were able to avoid them felt more in control.

It was also apparent that the *immediacy* and *severity of the consequences* of an attack influenced the level of parents' anxiety and their motivation to control and prevent attacks. As asthma attacks can be life-threatening, parents of asthmatic children have a stronger focus on preventing attacks in the immediate future (and less on long term lung function, particularly as many children's asthma improves or disappears with age). However, in the diabetes group, parents had a stronger focus on maintaining long-term blood glucose control, and were usually less concerned about immediate risks of preventing hypos, particularly as most were not serious (e.g. light-headedness as a symptom) and were easily remedied by giving the child something sweet.

A further feature of immediacy and severity where there are disease-specific differences is illustrated in Appendices 5.8 and 5.9. In Appendix 5.8 on page 86, Schematic Diagram 11 reiterates the point that the main focus of parents of asthmatic children is on preventing attacks (and these are the most severe and have the most immediate consequences). Therefore, the detection of triggers, prevention and consequences of attacks are temporally closely linked. The parents of asthmatic children receive immediate feedback about whether their recognition of symptoms was accurate and whether subsequent interventions (e.g. giving an inhaler) had been effective. This is likely to be self-reinforcing, and impact on parents' self efficacy.

However, as mentioned above, although parents did describe serious 'hypos', these often only happened on one occasion; parents learned from the experience and avoided the preceding circumstances in future. More commonly, parents described their child's blood glucose as 'being a bit low', which was easily corrected. The main concern of parents in the diabetes group was maintaining good long-term blood glucose control, motivated by fear of serious complications in later years; in general, they regarded short-term mild symptoms of hyper or hypoglycaemia as less serious, except insofar as these impacted on longer term blood glucose control. Also, observing an attack or periodic high or low blood glucose readings did not necessarily predict the HbA1c result obtained on their clinic visits. (HbA1c is a measure of longer-term blood glucose control). Therefore, some parents were pleasantly surprised by the HbA1c result, saying they and/or the child '*got away with it*' or '*were lucky*'. The reverse was also observed on occasion. As information about HbA1c is only obtained about every three months, parents do not have immediate feedback about their child's longer-term blood

glucose control. Therefore, parents may lack confidence and self-efficacy with regard to predicting and managing good blood glucose control.

Another disease-specific factor is the *degree of demand / effort required* to carry out the necessary treatment management tasks. This suggests that adherence should not be seen as a single concept, because different behaviours relating to adherence require different degrees of effort and create different demands (e.g. problem-solving, remembering task at non-specific times), as well as having different consequences. Where the demands are high and consequences not immediately obvious (and/or not severe) they may be more likely to be omitted. Parents feel guilty about omissions (often in this category), especially if an attack results from this. This contributes to parents' stress, especially if the child continues to be non-compliant.

In relation to the second question about why parents respond differently in similar situations, and how these responses influence or reflect their adjustment, some other illness-specific factors that have been identified from the data are illustrated in the diagrams in Appendices 5.8-5.12 on pages 86-90. In addition to the first point below (which was discussed earlier), further *illness and treatment-specific factors* have been identified:

- *the temporal relationship between observed signs / symptoms and relevant outcome indicators of wellness* (as discussed above)
- *consistency of patterns of symptom presentation* (i.e. can parent and child always recognise them?)
- *recognition / knowledge of triggers of attacks* (especially for the asthma group)
- *effectiveness of medication* (reported mainly by parents in the asthma group, although the effectiveness of the insulin regime was reported by some parents in the diabetes group)

In addition to illness-specific factors just reported, components of Schematic Diagrams 11-14 show some other groups of factors relevant to both illness groups that relate to parents' self-efficacy in managing the illness and the child's ability to adhere to treatment. With reference to point made earlier about how illnesses differ in the immediacy and severity of the consequences, this factor may also influence treatment adherence. Differences in the consequences of the child's non-adherence are shown in Appendix 5.12 on page 90, where Schematic Diagram 15 illustrates that, for the asthmatic children, omission of treatment management behaviours on an occasional basis (e.g. not taking their preventer inhaler)

normally had no immediate consequences. Some parents said they therefore found it difficult to insist that their child complied with this (i.e. one parent expressed the child's and to some extent her own perspective as, '*If it ain't broke, don't fix it*'). However, when chronic non-adherence led to an attack and hospitalisation, the parent expressed guilt and regret, sometimes leading to more confrontation with / nagging of their child. A similar issue was found with parents in the diabetic group. Although no diabetic child was fully compliant with all aspects of treatment, the areas of non-adherence (e.g. not rotating injection sites) usually did not have immediate consequences. The areas of treatment that, if omitted, would definitely result in serious, life-threatening consequences were undertaken by all children (with the exception of one male adolescent who omitted giving himself his insulin, which led to him being admitted to hospital in a very ill state).

Overall, the 5 schematic diagrams relating to treatment adherence (11-15) together show how illness-specific, individual and external factors may all interact and contribute to differences in parent adjustment. These factors are summarised below:

Individual difference factors:

- *individual aspects of the biology of their child*
- *child age or stage of development*
- *individual temperament or personality of their child* – e.g. easy-going, excitable
- *the responsiveness of their child to effective treatment* (i.e. even if adherence is good, the outcome for disease management is not always good)
- *perceived burden or complexity of treatment.* This links to the point made earlier about demand / effort of treatment tasks. Although on the face of it, one might regard the complexity and burden of diabetes treatment as being greater (and therefore an illness and treatment-specific factor), some parents of diabetic children did not perceive it as such. It's possible that impacting on the burden is the number of years since diagnosis – i.e. child gets 'fed up' with years of treatment.
- *previous and current externalising or internalising behaviour*
- *gender?* It is not yet clear whether this factor is relevant – there may be an interaction between age, gender and illness type
- *parents' judgements about what is important for the child* – giving the child responsibility and independence in treatment management (i.e. developmental focus) or parent taking personal control (i.e. illness management focus)

Events or external factors (although individual differences would impact on these):

- *not being well informed by health care professionals*
- *child's life experiences* (e.g. bereavement)
- *child's and parents' previous success or failure with treatment management*

A factor above where the significance is tenuous relates to gender; this was different for the two groups. It was found that the least effective shared control in the asthma group was in the group of teenage boys, and in the teenage girls in the diabetes group. A possible explanation is that some of teenage girls were reported to be very sensitive about their appearance, and so did not inject insulin in sites that would be visible if they wore fashionable clothing or swimsuits. Over-use of specific injection sites can cause unsightly lumps and bumps, and continued injections in these areas reduce insulin absorption and uptake into the blood (thus reducing good blood glucose control). Furthermore, some teenage girls were reported to be keen to lose weight; since conditions of high blood glucose / poor insulin uptake lead to weight loss, this may have led some teenage girls to be more non-adherent.

A possible explanation for asthmatic teenage boys adhering less to their treatment is that 'being sporty' was more often reported as being important for boys. Therefore, there would be a high degree of visibility (and probably frequency) of their treatment, as they would ideally need to self-administer inhalers prior to any sporting activities. It could be that by adolescence, they had reached a point where they found this unacceptable, particularly as they would have been doing this all their lives (since the average age of diagnosis in the asthma group is much earlier than in the diabetes group, i.e. about age 2 years). Thus, it is possible that there is an interaction between gender, age and illness type, but this would need further exploration.

It was notable that when considering the possible influence on adjustment of different illness features, none of the factors listed above refer to disease 'severity' or 'number of hospitalisations'. This is probably because factors that are indicative of severity have been reported by parents in the data from this Chapter, rather than parents expressing severity as a concept. Any findings about the impact on parents' adjustment of frequency of attacks and hospitalisation are likely to emerge from the data in the next Chapter.

It was apparent that parents faced with apparently similar circumstances and treatment demands did not always perceive them in the same way. For example, perception of the burden or complexity of treatment was described differently by some parents than others.

Some (for example parents of D_12 and D_13) said that the illness ‘ruled their lives’, whereas for others (for example the parents of D_6 and D_16), the treatment seemed to be less intrusive in their lives. Reasons for this are not really apparent from the data relating to this Chapter, but are likely to emerge from the analysis of data within Chapter 6. In other cases, there were clear differences in other experiences (relating to the factors listed above) that could account for individual differences in parents’ adjustment, even though the treatment demands were similar. As discussed, many of these factors were not controllable / predictable, which contributed to parent’s anxiety and low self-efficacy.

Key insights relevant to the theoretical model

Parent’s responses to treatment requirements and consequences

- As shown in the previous Chapter, parents actively try to find causes for perceived successes or failures. In the context of managing the priorities of their child’s treatment, parents take actions consistent with their interpretations.
- Where causative factors are not identifiable, controllable, and / or the consequences not severe, parents are less likely to take appropriate preventive action.
- Also, as reported in the last Chapter, some parents had to make difficult judgements about priorities (health or development). In this Chapter, this same issue arose in the context of whether to allow their child independence in treatment management (beneficial for development), when there were doubts about the child’s competence (risks for health).

Illness-specific factors influencing parents’ adjustment

- Parents consider that certain disease-specific or treatment-specific factors affect both their child’s and their own ability to predict symptoms and changes in the child’s health, to prevent attacks and promote good physical health.
- Where there are significant numbers of uncontrollable / unpredictable factors, (such as ineffective medication), parents experience low self-efficacy and high anxiety, particularly where the *consequences of failure are severe*.
- The *immediacy* of symptoms relative to preventive actions is relevant because it is helpful where parents can more easily see the relationship between events (triggers or symptoms) and their own actions (avoiding triggers, treating symptoms). Where this

relationship is not clear, parents experience low self-efficacy and high anxiety. A particular concerning group for parental mental health may be in cases where parents believe they and their child have been adherent to treatment, but this does not lead to good control of the illness.

- ***The degree of demand / effort required*** to carry out treatment management behaviours is important; this is related to the parents' ***perceived burden and complexity*** of the treatment management. Adherence should not be seen as a single concept, because tasks of low demand and low effort, with serious and/or immediate consequences are likely to be carried out more consistently.

Individual difference factors influencing parents' adjustment:

- As in the previous Chapter, parents believed that individual factors influenced their child's behaviour, which in this Chapter are shown to impact on treatment management.
- These factors include the child's age, stage of development, temperament, biology, a wish to be 'normal' and possibly gender in interaction with age and disease type.
- Where these factors resulted in the child sharing care effectively with the parent (or cooperating, where younger), treatment effectiveness tended to be better and parents experienced a higher sense of control and less stress. The reverse was also generally the case.

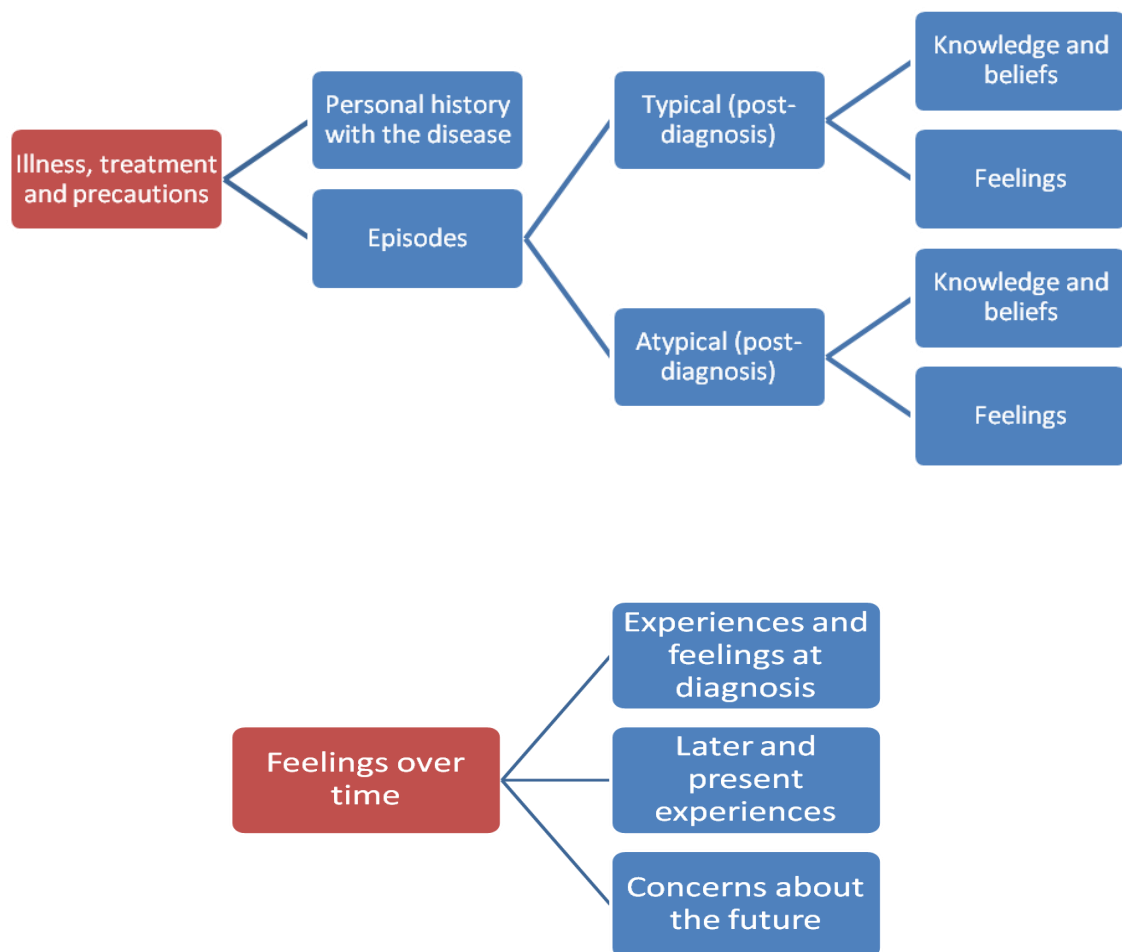
Events or external factors influencing parents' adjustment:

- As in the previous Chapter, parents considered that a range of external factors impacted on the ability for the child's and parents' experiences.
- In the context of managing and adhering to treatment, these included personal knowledge gained from health professionals, the child's life experiences, the child's previous or current internalising or externalising behaviour and the child's and parents' previous success or failure with treatment management
- These factors affect parental adjustment because they influence the success or otherwise of treatment management, parents' feelings of control and self-efficacy, which is related to the degree of parental anxiety.

CHAPTER 6: PARENTS' EXPERIENCE OF ILLNESS EPISODES, VARIATIONS AND TRAJECTORIES

6.1 INTRODUCTION

This Chapter will consist of the analysis of results of two themes and associated sub-themes relating to the child's illness episodes, variations and trajectories in the illness experience, as indicated in headings shown in the diagram below. The description and explanation of each of these will be presented in section 6.1.1.

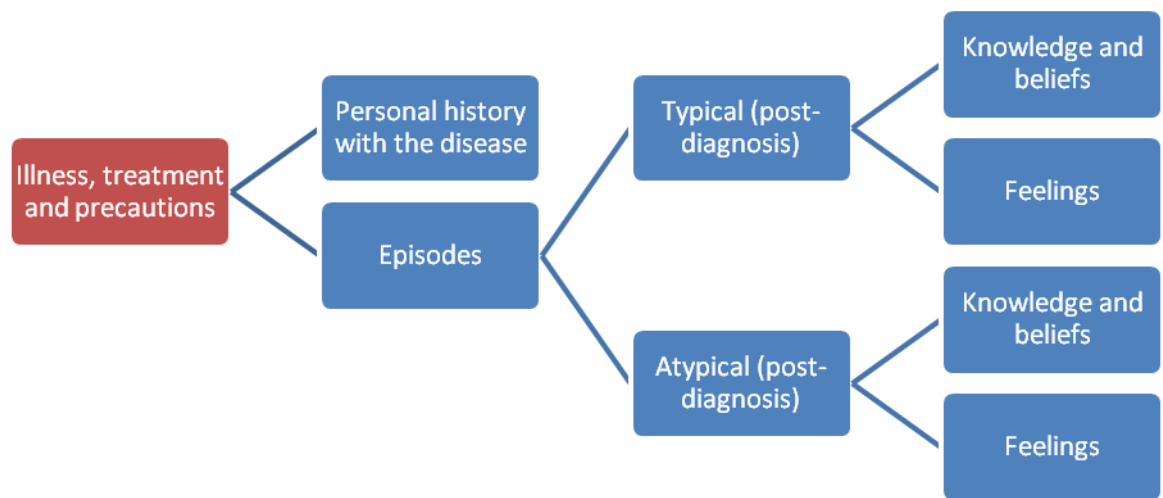


Consistent with the analytical approach introduced in Chapter 3 and followed in Chapters 4 and 5, a grounded theory methodology has been used, and will contribute to the theory about parental adjustment that was partially formulated in Chapters 4 and 5.

As in the previous chapters, the results of the asthma group and then the diabetes group will be reported and discussed. Following the presentation and analysis of each group’s results, there will be a summary relating to each sub-theme. The Chapter will end with a cross-group comparison, and overall summary of the sub-themes and any further additions to the developing theory.

6.1.1. Explanation of themes considered in this Chapter

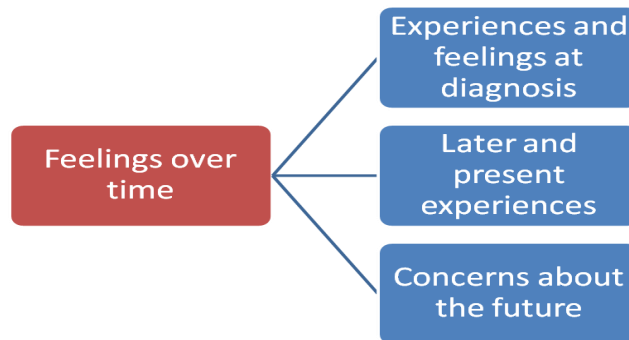
Illness, treatment and precautions



The theme of ‘Illness, treatment and precautions’ was identified in all parent interviews. Most spoke at length about their child’s illness and how it was managed. Many also recounted vivid experiences of episodes in their child’s illness history that occurred both typically (i.e. those happening on a frequent basis, which were not unexpected) and those occurring atypically (i.e. infrequent and / or unexpected events in a child’s illness history). For example, in some cases such episodes were atypical because they were few in number, whereas in other cases, this kind of episode happened often but the features of the episode were different from usual.

When describing these illness episodes, parent’s beliefs, attitudes and feelings about their child’s illness and its management were often expressed. Unexpected and atypical illness episodes appeared to have particular salience for parents in this regard, often leading to changed responses. It is therefore likely that these experiences and accompanying beliefs, attitudes and feelings will be influential in parental adjustment.

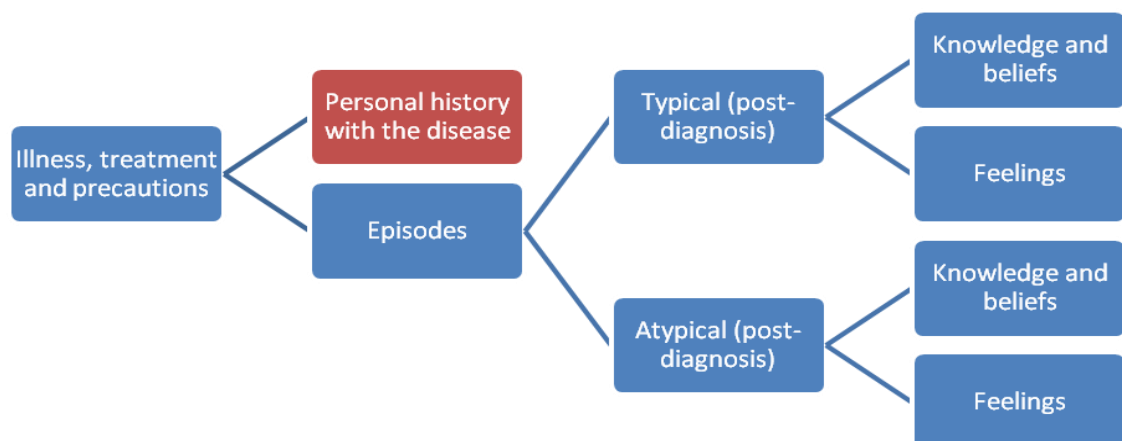
Feelings over time



During interviews, all parents spoke about their past and present experiences, and associated thoughts and feelings relating to their child’s illness and its management. They talked about how they felt in the ‘early days’, at the present time, and also their thoughts and feelings about the child’s future. Even after many years since their child’s diagnosis, many parents still recounted details of events and recalled emotions that were experienced at the time of diagnosis. Through talking about their present feelings and future concerns, it will be possible to identify a trajectory of how parents have adjusted following the initial diagnosis.

6.2 ILLNESS, TREATMENT AND PRECAUTIONS: PERSONAL HISTORY WITH THE DISEASE - ASTHMA GROUP

To recap from Section 6.1.1, under the broad theme of ‘Illness, treatment and precautions’, there are two sub-themes, as illustrated below. The first sub-theme to be discussed will be ‘Personal history with the disease’ in relation to the asthma group.



The sub-theme of ‘personal history with the disease’ was identified when it was noted that many parents reported a family history, and viewed this in both positive and negative ways. Although asthma is not an inherited illness, there is a strong tendency for atopic diseases (e.g. eczema, asthma, allergies) to run in families. This is the reason for the finding that most parents reported that they and / or the other parent had asthma or that one or more near relatives had asthma.

Overall, 10 parents discussed family history (A_1, A_2, A_3, A_7, A_9, A_10, A_11, A_12, A_14 and A_15). All but two of these respondents reported that there was a family history of asthma. In one case (A_10), relatives had eczema only, and in another case (A_3) the parent reported that there was no family history of asthma or other atopic illnesses. Six parents did not mention family history in the interview. Further information about this may be found in Appendix 6.1.

Parents discussed the impact of the family history on their beliefs, knowledge and skills, and attitudes / emotions. For some parents, the impact was positive (e.g. recognising asthma symptoms easily, feeling empathy), for others it was mixed or negative (e.g. worries about the life-threatening prospect of asthma due to a relative’s life-threatening attacks).

The following excerpt illustrates how a family history of asthma influenced a parent’s beliefs, meaning that she anticipated that one of her children would develop asthma. She describes her emotions as a result of memories of her own mother’s severe asthma, and how this helped her to cope with her child’s attacks:

Respondent	Interview Extract
<p>A_7</p> <p>Impact of family history on beliefs, emotions and coping</p>	<p><i>Parent describes first hospital admission for respiratory problems:</i></p> <p>M: They [doctors] were almost certain it was breathing problems and that she would more than likely end up with asthma. And my Mom’s a chronic asthmatic. Her Dad is, and her Dad’s Mom is as well. So, it’s in the family. So we expected one of them to end up with it.</p> <p><i>Parent describes the effect of family history on her emotions and coping:</i></p> <p>I: How did you help yourself get calm? [in hospital]</p> <p>M: Just by knowing that she’s in the best place, and that the doctors know what they’re doing. And they’re trained, obviously, and that</p>

	<p>she'd be OK. And I kept clinging onto that. I mean I saw my Mom die with asthma, and they brought... she was resuscitated. So, to see my Mom in that kind of state, it was also quite worrying to see my child like it. But luckily, she got bad but never as bad as my Mom. And I knew my Mom would be alright. My Mom kept the faith with me as well. She kept saying, 'She will be fine. She's a fighter.' And that is what we hung onto.</p> <p>I: It sounds like your Mom's been a big support to you, really.</p> <p>M: She's been fantastic, where the asthma's concerned, 'cause my Mom's suffered since she was 16. She's had loads of trips in hospital. As children, we always used to visit her in hospital, wired up to machines. And once I went in with her. I was about 17 at the time. And she actually stopped breathing. And I was ushered out of the room while they resuscitated her. And that was absolutely frightening. I was really scared. So, it was thanks to her I learned to keep calm and that rubbed off and helped [child's name] to be calm, because if I was calm, she was calm, which was a good help.</p>
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The above parent reported that her husband also had asthma, and although this was less severe than the child's, the father's experience of the illness enabled him to identify asthma symptoms readily, and he was well prepared to cope with the child's asthma attacks. This was also reported by the parents of A_2, whose father also had asthma. According to these parents, this had a very positive influence on their family's coping.

The mother of A_11 noted the similarity of her son's asthma to that of his father, which led her to hope that he would 'grow out of it', as his father had done. Parents' attitudes were also influenced by having asthma themselves. The mother of A_1 reported her belief that having asthma herself influenced her 'let's get on with it' attitude.

In summary, it seemed that where one of a child's parents had a similar degree of asthma severity as the child, parents tended to view their family history as a factor in enhancing their knowledge, skills, or attitudes concerning asthma management.

One parent (A_9) had more distant relatives with asthma, whose asthma varied in severity. As a result of having one relative with severe asthma, the parent 'knew how serious asthma could be'. However, she said she had not expected her child's asthma to be as serious as it was, presumably because she was making comparisons of her child with other, more mildly affected relatives. It's possible that this was a factor in her not being alert to her son's deteriorating respiratory function (as discussed in the previous Chapter). Alternatively the parent may have been trying not to think her child could have serious asthma, due to a self-protective / defensive response.

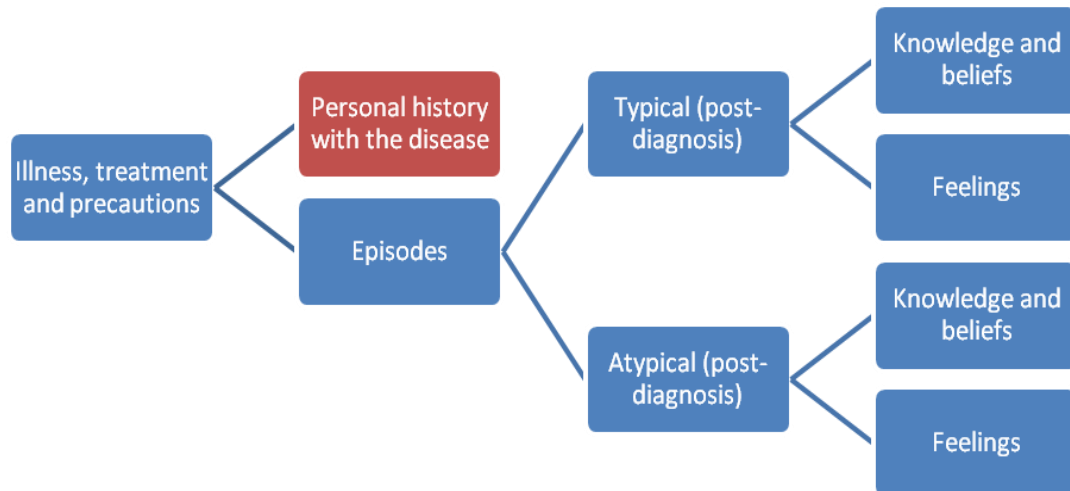
Finally, for some parents, their child's asthma was more severe than with any other family member (A_12, A_14, A_15). In the case of A_14, every immediate family member had asthma, but none as severe as the child referred to in the interview. The parent did feel however that her own asthma history affected her beliefs about her child's future illness course (i.e. although getting better in late adolescence, it will come back again in adulthood). The parent of A_15 reported that the child's father (from whom she had been separated for most of her child's life) had asthma, but it had been very mild and she had never observed an attack. Consequently, the mother felt shocked at the severity of her child's asthma, she felt she knew very little and did not realise that asthma could be life-threatening. She considered that this influenced her coping at the time of her child's diagnosis.

6.2.1. Summary of personal history with the disease and parent responses

Most of the children in this sample had a parent or near relative with asthma or other atopic disease. This family history influenced parents' beliefs, knowledge and skills and their attitudes / emotions. Where close family members had asthma, this was often helpful in the parents' understanding and coping with the illness. However, where a more distant relative had asthma (often less severe than that of their child), this sometimes led to some less positive consequences for parents. For example, some had inappropriate expectations of the potential severity of their child's asthma, fewer management and coping skills and felt more shocked about their child's illness severity. Better publicly available information about asthma and proactive educational interventions in childbearing families with a history of asthma may be a worthwhile consideration for health educators.

6.3 ILLNESS, TREATMENT AND PRECAUTIONS - PERSONAL HISTORY WITH THE DISEASE- DIABETES GROUP

The results of the first sub-theme to be discussed relate to ‘Personal history with the disease’, which in this context concerns parents’ experience of diabetes in relatives other than their child.



Some parents in the diabetes group talked about their family history with diabetes, either of Type 2 diabetes only (which normally has an onset in adulthood and does not usually require insulin administration) (D_3, D_4) or both Type 2 and Type 1 (which is the type children usually have, requiring insulin administration) (D_7, D_14). Having a family history is not typical in this sample; probably the reason is that although there is a familial tendency in the development of diabetes, the disease is not inherited.

Nevertheless, a number of parents or their acquaintances thought that diabetes was inherited (D_1, D_8, D_9, D_13). After diagnosis, three of these parents questioned how and why their child developed the illness and actively searched their family history for relatives who had diabetes, apparently to try to find a reason for their child developing the disease.

Parents’ experiences of having a family history of diabetes or not was related to varying beliefs, knowledge and skills and attitudes / emotions. The following two extracts (D_8, D_3 and D_4) show examples of respondents with and without a family history, and their responses to this.

These participants had no known family history (D_8), and discussed their thoughts and feelings about the heritability of diabetes:

Respondent	Interview Extract
<p>D_8</p> <p>No known family history; not knowing symptoms or understanding cause; not looking for someone to blame</p>	<p>M: The thing was, people didn't know - our friends and family didn't know really what diabetes was, did they?</p> <p>F: No.</p> <p>M: And we weren't knowledgeable in it. So it was...</p> <p>F: I mean we went through this sort of family searching, you know. Has there been diabetes in the family? And...</p> <p>C: It's from your side of the family (looking at father).</p> <p>M: We think.</p> <p>F: I don't know, I have no proof, but somebody said to me I've got some cousins who live in Belgium and apparently some of their predecessors had diabetes. But I mean I don't know.</p> <p>I: It's not a directly inherited thing anyway. You know, there's so many factors involved it in really. Sometimes there's what they call a familial tendency; some people just have it.</p> <p>F: I think it just makes it - heightens the possibility, that's all.</p> <p>M: If it's not hereditary, why was [child's name] told she stands a one in twenty chance then of producing a child with diabetes?</p> <p>F: Well it's because it gives you a heightened chance.</p> <p>I: A higher chance, but some people just have it, and there's nobody who can find anything in their background then.</p> <p>M: Obviously it makes you intrigued to find somebody, doesn't it?</p> <p>F: To me, no particularly, to me it's almost like you're looking for someone to blame.</p> <p>M: No.</p> <p>F: And that's pointless. It doesn't achieve anything, does it? You know, I mean, since it's very self-defeating, I can't really see the point of that.</p>

The fact of having no family history affected these parents' lack of knowledge of diabetes at the time of their child's diagnosis, a point made by other respondents (D_1, D_5). A number of parents expressed annoyance that others did not know the cause of Type 1 diabetes (i.e. thinking it was caused by their feeding the child the wrong foods or their child over-eating) (e.g. D_1), so this could be a reason why some parents looked for an alternative cause, in order to explain it to others. The following parent (D_3), at the time of diagnosis, herself suspected that she might have caused her child's diabetes in some way, and was relieved that this was not the case:

Respondent	Interview Extract
<p>D_3</p> <p>No family history of Type 1: relief at feeling not to blame</p>	<p>M: Because I felt, with very little knowledge of diabetes, that I'd caused it, and that I'd been feeding her wrong for the past 11 years, and that I was in some way responsible for it. And without really having to ask that, the consultant sat on the bed; it was very comfortable, it was very, you know it wasn't distant. And he sort of put his arm around [child's name's] shoulder and he said, 'You know, I'm just going to explain a few things'. And it makes you automatically, because of that physical proximity, and he said, 'And there's no way that anybody's at fault here. It's one of these things, you've got Type I; it's nothing we could have done to have stopped it; it's not eating too many sweets when you were little.' And all that, it sounds very superficial, it's really all that you want to hear, that it's beyond your control and you've got it for whatever reason, but you had no part to play in that. So that was music to the ears.</p>

This contrasts with the feelings expressed by another parent, whose father had diabetes, and who believed this was the reason for his son acquiring it:

Respondent	Interview Extract
<p>D_4</p> <p>Father has family history of Type 2 diabetes</p>	<p><i>Mother describes her recognition of diabetes symptoms in her child, prior to diagnosis:</i></p> <p>M: Well the most - one of the most traumatic things for me was I suspected - my father's - my husband's father had diabetes.</p> <p><i>Later in the interview:</i></p> <p>F: But I've now spent five years with two things hanging over me. One is the guilt of my carrying the genes - 'cause my father was a diabetic.</p> <p>M: That's not your fault.</p> <p><i>Later in the interview:</i></p>

	<p>F: My baggage includes remembering my mother nurse my father through blindness and death with this. And measuring dollops of mashed potato and things - and all the paraphernalia. You know, that was quite a big thing.</p> <p>M: Which was a lot worse then.</p>
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For this respondent, it was evident that he was feeling very guilty, believing that his genes were the cause of his son's diabetes, which was accentuated by recalling of the demands of managing diabetes, with its 'paraphernalia', and of the apparently traumatic experiences of observing his father dying from complications of the disease. It was noted that immediately after the end of the above extract, the father began talking about his efforts to seek professional psychological help (with no intervening questions from the interviewer or comments from his spouse). Although he did not specifically state that this was related to his feelings of self-blame, this was the interviewer's impression due to its proximity to the father's discussion of this issue. These parents reported later in the interview that they were frequently alert to possible diabetes symptoms in their second child, due to worries about genetic links. This was evidently a source of some stress.

The two parents with a family history of diabetes both recognised their child's diabetes symptoms and suspected the diagnosis prior to seeking medical advice. The parent of D_7 described how she tried to explain away the early symptoms for some time before seeking medical advice (i.e. he was just thirsty), even though she strongly suspected that her son had diabetes, and the mother of D_4, even after discovering her child had sugar in his urine (after buying a urine testing kit), tried to explain it away by suggesting it was caused by her child's response to a chemical in the floor cleaner. The parents' upsetting experiences of the complications and potentially life-limiting effects of diabetes in relatives could be an explanation for these responses.

6.3.1. Summary of personal history with the disease and parent responses

A small number of parents discussed the presence or absence of a family history of diabetes, and how this affected their beliefs, knowledge, attitudes and emotions. Those without a family history (or whose acquaintances thought diabetes was inherited) often investigated whether any relatives had diabetes. For some parents, this may have been an attempt to explain why their child acquired diabetes or to correct others' conceptions that Type 1 diabetes was caused by eating the wrong foods or overeating. Near the time of diagnosis,

those with a family history showed reluctance to accept that their child could have diabetes, as they recalled the negative outcomes of the disease in their family members.

6.4 ILLNESS TREATMENT AND PRECAUTIONS: PERSONAL HISTORY WITH THE DISEASE - COMPARISON OF ASTHMA AND DIABETES GROUPS

Parents of both asthmatic and diabetic children discussed personal or family history of the disease, although this was somewhat more frequently reported in the asthma group. This is likely to be due to differences in patterns of heritability. Parents in both groups where another family member had the disease commented that this enabled them to more readily identify symptoms in their child.

In the asthma group, this related to recognising signs of an impending attack, whereas in the diabetes group, this related to identifying symptoms prior to diagnosis. This group of parents of asthmatic children seemed to generally view the family history in a positive way. Having personal knowledge from their own or another family member's asthma experience was seen as valuable in managing and coping with the child's illness.

In contrast, the two parents in the diabetes group who had relatives with diabetes did not see this experience in a positive way. Possibly, this was because they both had distressing recollections of the impact of diabetes on their relative's life, and the complications and death from the disease. This led these parents to initially not want to consider that their child had diabetes, even though they strongly suspected this prior to diagnosis. However, only one parent in the asthma group (A_7) discussed their distress concerning a relative's asthma (who had experienced worse asthma severity than their child's); she did not describe a reluctance to identify early symptoms as being due to asthma.

One reason for this group difference could be that asthma varies in severity, and often improves or disappears in adulthood. Most of these parents reported that their relative had either less severe asthma or had experienced a similar level of severity to their child's, and sometimes the relative no longer had asthma. These parents may have felt more positive about the family history because they compared their child to their relative, leading them to hope for their child's recovery, or at least an improvement.

In contrast, the children with diabetes could only hope to avoid worsening of the disease and their parents' experiences of negative outcomes led to their initial distress and desire not to

interpret the symptoms as being due to diabetes. Also, as mentioned previously, the demands and unpleasantness of managing diabetes are in most cases greater than with asthma. Therefore, the anticipation of this may also have influenced these parent responses. There was no equivalent response from the asthma group, except perhaps A_9, who did not appreciate the severity and worsening of her child's asthma, although she said she knew asthma could be serious.

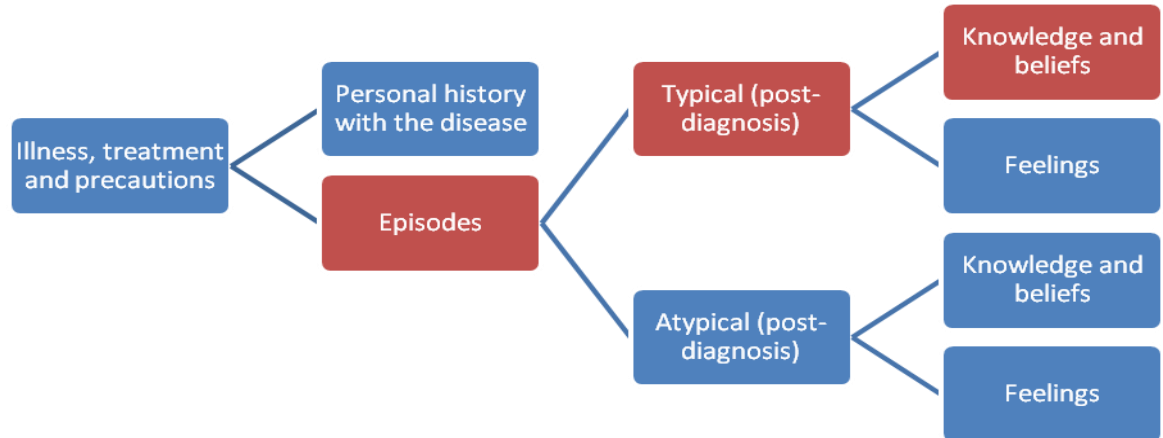
A further group difference was that in the diabetes group, the two parents with a family history of diabetes blamed themselves for causing their child to acquire the disease, which led to some degree of distress. In contrast, when one parent (D_3) learned that she was in no way to blame, she was greatly relieved. Interestingly, no parents in the asthma group said that they blamed themselves or their family member for their child's asthma.

Two possible explanations are offered; the first relates to the parent's expectations at the time of diagnosis and the second about the parents' feelings about the consequences of the diagnosis. The parents in the asthma group were often aware that a child they might conceive could develop asthma (due to their commonly expressed knowledge of a genetic predisposition to acquire it). For example, the parent of A_7 said, '*we expected one of them [offspring] to end up with it*'. Being able to anticipate a child might get a disease enables a parent to prepare themselves emotionally and cognitively for this possibility, which could enhance coping and reduce defensive and self-blame responses. As the genetic pattern is different with Type 1 diabetes, parents may not have similarly anticipated or prepared themselves in the same way for such an occurrence.

The second possible explanation for differences in self-blame relates to feelings about the consequences of the diagnosis. Relatives in the asthma group had asthma that was well controlled, so it may not have had or at least no longer had a serious impact on their lives. On the other hand, the two parents of diabetic children who had a relative with diabetes had not observed such a positive outcome. Therefore, self-blame may be more likely when the parent perceived that the consequences of the disease in adulthood were greater, so blaming themselves for the anticipated impact on their child's future.

In summary, although parents in both groups who had a family history of the disease had greater knowledge, the attitudes, emotional response and coping differed, with the parents in the asthma group reporting more positive responses. Thus, it appears that there may be an interaction between family history, disease characteristics and their variability, and inheritance patterns.

6.5. ILLNESS, TREATMENT AND PRECAUTIONS: EPISODES – TYPICAL (POST-DIAGNOSIS), KNOWLEDGE AND BELIEFS – ASTHMA GROUP



The next sub-theme to be discussed relates to episodes of acute symptoms or prevention of health problems in the child, as explained in Section 6.1.1. The first sub-theme of episodes to be discussed relates to those of the type that occurred regularly and with symptoms that parents expected from prior experience of this nature (i.e. were typical). This sub-theme does not include episodes that led up to a diagnosis, as these episodes were coded under the theme of ‘Feelings over time’.

The sub-theme ‘episodes’ had originally been coded as ‘Perception of disease and symptoms.’ However, during the coding process, it soon became clear that most of the content that would be coded as this sub-theme related to particular illness episodes, which were often described with a high level of emotional content as well as knowledge. Furthermore, it became apparent that parents were describing two kinds of episodes – one type that was fairly predictable and occurred regularly, and another type that was unpredictable and occurred unexpectedly. Each seemed to be associated with different kinds of knowledge and feelings. Hence, it seemed valuable to consider these two kinds of episodes separately.

The number and nature of typical episodes

Ten parents or couples described knowledge or beliefs in the context of episodes that were categorised as typical (A_1, A_2, A_4, A_5, A_8, A_11, A_12, A_14, A_15 and A_16). See Appendix 6.3 for further information. Parents reported that these episodes occurred relatively

frequently and that their characteristics and features were fairly predictable. In three cases (A_8, A_14 and A_15), composite episodes were described. In these descriptions, parents discussed similar situations at the same time, for example the parents of A_8 talked about the two episodes where their son had an attack in a restaurant and had to be admitted to hospital. The parents described similar features of these episodes, so this is possibly the reason why they discussed the episodes together.

Four kinds of typical episodes were described:

- Episodes related to preventing an attack – no medical intervention (A_1, A_8 and A_12)
- Episode related to an acute attack, where there was no medical intervention (i.e. parent managed the attack on their own) (A_1, A_8, A_12, A_14 and A_15)
- Episodes related to an acute attack or worsening symptoms, where the GP was seen (A_4, A_11, A_14 and A_15)
- Episodes related to an acute attack, resulting in a hospital admission (A_2, A_5, A_8, A_11, A_15 and A_16)

It is perhaps worth clarifying at this stage that for some children, regular hospital admissions for asthma attacks were typical. For example, the child of A_2 had ten hospital admissions for asthma in the previous year. For other children, an asthma attack resulting in hospital admission was rare, so in these cases the episode was coded as ‘atypical’. Therefore, it is important to recognise that the differences between typical and atypical episodes do not necessarily relate to the seriousness of the episode but whether the parent had commonly experienced such episodes previously, and could therefore predict the nature and outcome of the episode.

This distinction could be important, as in at least some typical episodes parents are likely to have a lower sense of control than when the episodes are unexpected or atypical. This is because if, for example, asthma attacks happen regularly, the parent might think that they haven’t been able to control the disease symptoms. A lower sense of control might influence a parents’ stress and coping during the episode. On the other hand, being able to predict the onset and outcomes of typical episodes might make parents feel more confident and less anxious, because having advance expectations can enable them to prepare themselves emotionally and behaviourally for an anticipated episode.

Typical episodes – knowledge and beliefs

Three kinds of knowledge and beliefs were expressed by parents:

- *Symptoms, treatment and causes in relation to the episode (expressed by 9 parents / couples)*
- *Risks and consequences of the episode (expressed by 2 parents)*
- *Actions or behaviours of doctors, the child or other people in relation to the episode (expressed by 8 parents)*

Symptoms, treatment and causes in relation to the episode

All but one of these ten parents / couples referred in their description to their child's drugs, treatment and / or attack prevention, often showing a high degree of medical knowledge. Most of these parents described their child's symptoms, such as those relating to the onset of an attack. Three parents also described that they were confident to make independent treatment decisions without additional medical advice (A_12, A_14 and A_15), possibly due to their extensive experience of managing asthma attacks. The following example of A_15 illustrates this point:

Respondent	Interview Extract
<p>A_15</p> <p>Demonstrating medication knowledge and ability to make independent decisions</p>	<p><i>Parent recognises onset of attack:</i></p> <p>M: When we first came out here [to the UK], because there was quite a few times where he was wheezy and the Ventolin wasn't helping and the preventive stuff wasn't helping and I thought, 'OK, what he needs is a nebuliser'.</p> <p><i>Parent discriminates between the benefits of different sorts of medication:</i></p> <p>M: You see, the difference between a nebuliser and a pump, even if it's in an aero chamber, is if you're feeling a little bit wheezy, a pump is better. But if you're having an attack and you're panicking, you know, this is very short. And if you're panicking and you can't breathe, by the time you get around to it, you're not getting as much as you should, whereas a nebuliser, and it's not just what you're breathing in, it's also the noise, the noise has a hypnotic effect, and it calms you down. And as you calm down, you're getting in that constant... (breathes in).</p>

Four parents (A_5, A_8, A_12 and A_14) also discussed what they believed had caused the episode – normally a combination of external and child-specific factors, such as with the child of A_5 who touched a horse because he felt like it (child-specific), but was allergic to it (external factor).

Parental knowledge and beliefs were also shown in relation to episodes involving preventing attacks (A_1, A_8, and A_12). Again, parents often made independent decisions about the best course of action whilst trying to balance risk and benefit for the child in terms of promoting normality, as in the case of A_8:

Respondent	Interview Extract
<p>A_8</p> <p>Balancing risks and benefits in decision-making about prevention</p>	<p>F: [child’s name] likes these apple puffs from Tesco. Anything in Tesco from the bakery counter says, ‘Do not eat if you have allergies because we cannot guarantee anything at all’. Well, if you follow those instructions, you’d never eat anything. Because everything always says, ‘May contain traces...’. Everything says this. So.. he likes those, and despite the fact that they use nuts in the bakery counter and there is always a chance of cross contamination. And so he was about to eat one the other day, and he always has a look at it, and there were quite big nuts embedded in the pastry. A pecan, as it happens. Well, he might be perfectly alright with it, but he spotted it and we cut it out and he ate the rest of it. So that seems to me, that’s appropriate. Avoid these obvious risks by quick inspection, you know. Even so, you might nonetheless, without knowing it, eat one. Well, that’s a risk that you might take. And it might have a bad effect or it might not. We just don’t know. But if it does, then you always have treatment with you.</p> <p>M: I think if it said, ‘may contain peanuts’, we wouldn’t. If it says, ‘sesame seeds and nuts’, then we’d have a go, because we’re pretty sure that he’s probably alright with tree nuts. But if it said peanuts, we would keep away from it.</p> <p>F: Well, that’s what I mean. That is what we believe is the more serious area.</p> <p>I: So it sounds like you take a more balanced view of life than say, some of these doctors who would seem to want to restrict your life to some extent.*</p> <p>M: My point about that is you do find yourself in that position, that you don’t just go to hospital and you’re getting a view of what you do. It’s that you are, you have to make up your mind yourself you know.</p>

* Parents had earlier described how one doctor thought they should never eat out in a restaurant and never take any risks with foods.

Risks and consequences of the episode (asthma attack)

In two cases where the parent described when their child had to be admitted to hospital due to an asthma attack (A_11 and A_16), they talked about the risks that they believed were present due to hospitalisation. In both cases, the parents believed their child was exposed to infection risks, as they considered either that the hospital was not a clean place or that other children on the ward with infectious diseases could transmit infection to their child. One parent additionally believed that there were negative psychological consequences on her child of the hospital admission (A_16), possibly related to the frequency of such admissions and the child's young age.

Actions or behaviours of doctors, the child or other people in relation to the episode

Eight of the ten parents / couples discussed their beliefs about the actions or behaviours of doctors, their child or other people connected with the episode. Some parents expressed beliefs about how competent doctors were to make appropriate decisions concerning their child's care. These parents believed that doctors did not always know what was best for their child, and should appreciate the parents' experience and knowledge more (A_2, A_5, A_8, A_14, and A_15), or provide more information (A_16).

The following example illustrates this point:

Respondent	Interview Extract
A_14 Parent believes own knowledge and experience is not valued by doctors.	M: No, and I'm not one that runs to the doctor every five minutes, you know. I've managed four children's asthma, so I know when to seek help. So that when you do say, 'I'm not quite happy. Something's not quite right,' and you get told, 'Oh, give her a drink of water. Sit her up all night. She'll be fine'. I: So you feel they're not really listening to you. M: No, some of them are good. Some of them are very good, and say, 'Here's a prescription. Get on with it', and we know where we are, and others, well, no, 'What do you think you're doing? I'm the doctor, you're the patient', kind of thing. And that's difficult, especially when you've had something like 16, 17 years of dealing with it.

Parents also discussed their beliefs about the relationship between doctors and parents (A_4, A_8, A_14 and A_15). In one case, a parent who was a health professional felt she was trusted by the doctor to manage treatment appropriately, but she wished the doctor would not leave it to her to decide about discharge timing. Others believed that you just had to trust

doctors (A_15), or had to be assertive with doctors and make up your own mind (A_8, A_14). This was shown in the previous excerpt of A_8.

Finally, some parents expressed beliefs about others' lack of knowledge or irresponsibility, which put the child at risk (A_1, A_8), or their child's limited ability in some scenarios to respond appropriately to prevent or manage attacks (A_2, A_5 and A_8), although the parents of A_8 felt their son was able to weigh up risks.

6.5.1. Summary of typical episodes – knowledge and beliefs – Asthma Group

Parents described five kinds of typical episodes. Four of these related to events, actions and consequences of preventing or dealing with asthma attacks or worsening symptoms. For episodes involving attacks, parents managed some of these on their own, and in others their child needed to visit a GP or be admitted to hospital. One episode described by one parent was related to another health problem.

Three kinds of knowledge and beliefs were expressed by parents:

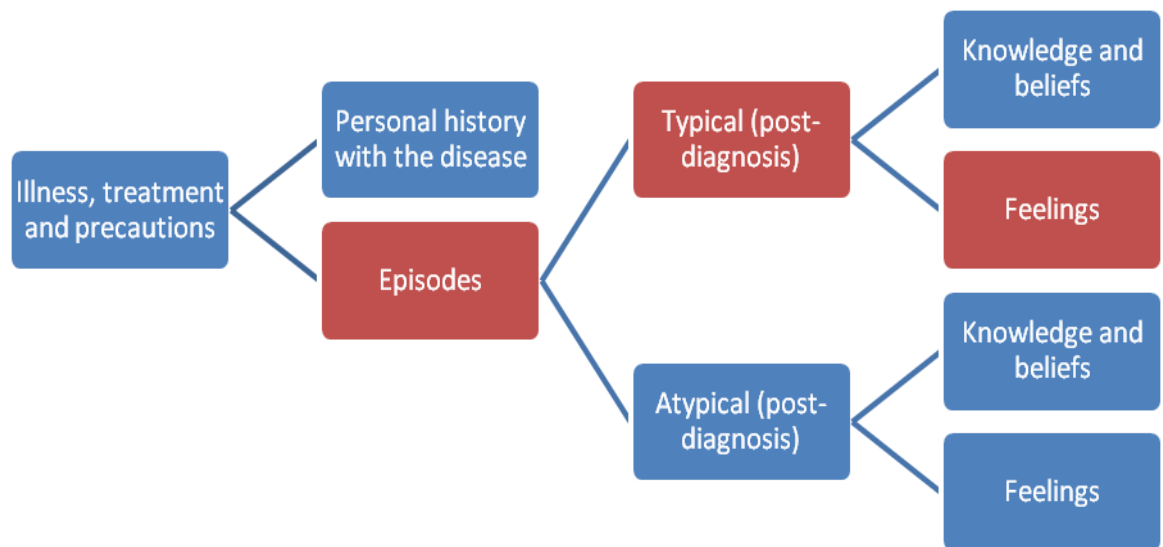
- *Symptoms, treatment and causes in relation to the episode*
- *Risks and consequences of the episode*
- *Actions or behaviours of doctors, the child or other people in relation to the episode*

Nearly all parents described their child's symptoms, causes of attacks and treatment, showing a high degree of accurate knowledge. This led many parents to feel confident in managing their child's treatment and making independent decisions on their own, for example in relation to medication type or dosage. This perhaps was one reason why a number of parents felt that doctors did not fully appreciate and acknowledge the parents' competence. Many parents believed that doctors did not always know what was best for their child, and should appreciate the parents' experience and knowledge more than they did.

Additionally, parents often made quite sophisticated judgements about risks, balancing their child's medical needs and risks against benefits for their child's psychological or social wellbeing. For example, the father of A_8 described how he allowed his child to eat pastries with pecan nuts on top (when he was allergic to peanuts), provided he removed the nuts. It was a risk, but a measured one. Similarly, the parent of A_2 allowed her child to play with his grandmother's dog, even though he was moderately allergic to animals. In cases such as this, the 'received opinion' might have been to have avoided these risks, but parents believed

it was better for their child to experience them in these contexts. It's possible that medical practitioners do not have the same perspective as parents sometimes because they focus more strongly on the medical and physical health consequences, whereas parents may take greater account of overall consequences for the child's wellbeing.

6.6 ILLNESS, TREATMENT AND PRECAUTIONS: EPISODES – TYPICAL (POST-DIAGNOSIS), FEELINGS – ASTHMA GROUP



The number and nature of typical episodes

Nine parents expressed feelings whilst describing typical episodes (A_2, A_4, A_5, A_8, A_11, A_12, A_14, A_15 and A_16, as indicated in Appendix 6.4. The context of the expression of these feelings was within four kinds of episodes:

- An episode related to preventing an attack – no medical intervention (A_8)
- Episode related to an acute attack, where there was no medical intervention (i.e. parent managed the attack on their own) (A_5, A_12, A_14 and A_15)
- Episodes related to an acute attack or worsening symptoms, where the GP was seen (A_4, A_11, A_14 and A_15)
- Episodes related to an acute attack, resulting in a hospital admission (A_2, A_5, A_11, A_15 and A_16)

Typical episodes – feelings

Five kinds of feelings were expressed by parents:

- *Worry, distress and anxious behaviours (expressed by 8 parents)*
- *Frustration, annoyance or anger (expressed by 5 parents)*
- *Sadness and disappointment (expressed by 5 parents)*
- *Discomfort (expressed by 3 parents)*
- *Positive and neutral feelings (expressed by 7 parents)*

Worry, distress and anxious behaviours (expressed by 8 parents)

Whilst there were some instances of parents feeling initial fear or panic in the context of an asthma attack, feelings expressed tended to relate to more general worries, including about hypothetical scenarios or future risks:

- fear at the onset of attacks or panicking if symptoms were out of control (A_11, A_12, A_14)
- stressed about difficulties of not being able to get medical attention easily or quickly (A_4, A_11, A_14)
- feel anxious in risky situations but able to control anxiety (A_8)
- worries about child's limited assertiveness in risky situations (A_8)
- worry about the infection risks in hospital (A_10, A_16)
- anxious health monitoring or health treatment behaviour (A_16)
- concern about not letting the child see how anxious the parent was (A_2, A_8)
- feeling unable to cope with stress of risky situation (A_8)
- worry about knock-on effects of repeated asthma attacks (A_4)
- feeling the burden of responsibility, wanting to share it more with doctors (A_4)
- distress when child having procedures involving needles (A_2)

The following extract illustrates a number of the above feelings, and shows how in 'typical' episodes, the worries are often wider, even though the central event might be an asthma attack or worsening health situation (i.e. having to get the child to the doctor's in the snow, in this example).

Respondent	Interview Extract
<p>A_4</p> <p>Worries about access to doctor in conjunction with those that are more general</p>	<p>M: Um, she had a bad run when she was about 9. I think that was very difficult, because I think I probably would have felt quite under-supported at that time. Do you remember it snowing, and I had to put you in the sled and get you to the Doctor's?</p> <p>C: Yeah.</p> <p>M: You know, the roads were...</p> <p>I: The roads were blocked.</p> <p>M: Yeah, and I couldn't get my car out and I do remember feeling...and she was off school for a very long time then.</p> <p>I: That's when she was off sick for a long time.</p> <p>M: Yeah, she was then. And there were probably other emotional issues going on, sort of interpersonal relationships going on when one was overlapping the other a bit.</p> <p>I: Within your family.</p> <p>M: Yeah.</p> <p>I: So, that made you feel quite....?</p> <p>M: Well, probably low anyway, and you lose that sort of self-confidence and self-esteem and you worry about the knock-on effects and you know, it was a bit of a horrible time.</p> <p>I: Yeah.</p> <p>M: Especially having to get you to the doctor's on the sledge. I had to push you up the hill. We live at the bottom of a hill; good coming back down though.</p>

Frustration, annoyance or anger (expressed by 5 parents)

Most feelings of frustration or annoyance were connected with interactions with doctors:

- Frustration with doctors (e.g. not enough information, inconsistent advice (A_16))
- Annoyed with doctors, for example when they prioritise differently, disagree with parent and / or don't feel doctors respect their experience (A_5, A_11, A_14, A_15)
- Frustrated with holiday insurance companies who won't insure child (A_14)

The following example is an illustration of the frustration parents sometimes expressed about not being believed by doctors or where they think their competence is not being respected by

them. This excerpt refers to a ‘composite’ episode, i.e. where parents discussed similar situations at the same time:

Respondent	Interview Extract
<p>A_5</p> <p>Frustration and annoyance with doctors</p>	<p>M: And the biggest struggle I have is when he’s bad, I have to ring up my doctor and they don’t believe me, what drugs he’s on. I get fed up of arguing with them. I take him into A&E and I drop all the tablets on the table and I say, ‘This is what he’s on. Now you can see what he’s on’, because they don’t believe me.</p> <p>I: They think he’s on too high a dosage or something?</p> <p>M: Yes. They say, ‘He’s only a fourteen year old lad, or thirteen year old lad, he cannot be talking what a grown man will be taking’, and I keep saying, ‘This is what he is on. I’m fed up of telling you people what he’s on. He is on these drugs’.</p> <p>I: So it sounds like sometimes it’s quite difficult to talk to health care professionals because they don’t always listen to you or believe you.</p> <p>M: Yeah. The last incident I had was them going on and on and on about laminate flooring*. And I thought, ‘stop talking about laminate flooring and treat his illness, what he’s got today’. It’s not about laminate flooring, but sometimes they seem to keep going ‘round in circles all the time, and that really annoys me.</p>

* *Laminate flooring rather than carpets may reduce dust mites and other allergens in the home that could trigger asthma attacks.*

Sadness and disappointment (expressed by 5 parents)

Feelings of this type were not commonly expressed in the context of these episodes, but when the parent did describe them, the feelings were related to sadness for the child or another child, and in a couple of cases for the parent themselves. The extract from A_4 (two extracts previously) illustrates the penultimate point below.

- Sad when sees the same ill child in hospital on each admission (A_16)
- Sad about child having to cope with disappointment (A_8)
- Sad at what child had to endure in hospital (A_15)
- Felt low, lacking in self-confidence and self-esteem when asthma control was poor (A_4)
- Feels disappointed at limited support by others (A_2)

Discomfort (expressed by 3 parents)

Two parents mentioned that they were uncomfortable in hospital environments (i.e. uncomfortable sleeping or bathing arrangements), and one suffered from lack of sleep due to their child's wakefulness in connection with their asthma.

- Discomfort in hospital environment (A_15, A_16)
- Disturbed by disruptive night-times (A_14)

Positive and neutral feelings (expressed by 7 parents)

All of these parents also expressed negative emotions (as detailed above). In some cases, parents expressed both negative and positive emotions about the same thing (such as feeling distressed, but also supported by family, or feeling sad when seeing another sick child, but this reminded them their own child could be worse off). Where this occurred, the respondent's code is marked with a * symbol in the list below.

Positive and neutral feelings expressed were:

- Feeling pleased that child can express feelings about disappointment (A_8*)
- Reminding self that other children are worse off than own child, and also own child won't be in hospital for long (A_16*)
- Feels able to help, by 'playing down' or normalising hospital experience (A_16*)
- Feels better when can talk about distress with own mother (A_2*)
- Feel positive when able to calm child during attack; generally feels confident (A_14)
- Feeling of relief when episode is over (A_11*)
- Thankful about health improvement, and for family support at stressful times (A_15*)

The following extract illustrates how some parents experienced both negative and positive emotions about the same thing:

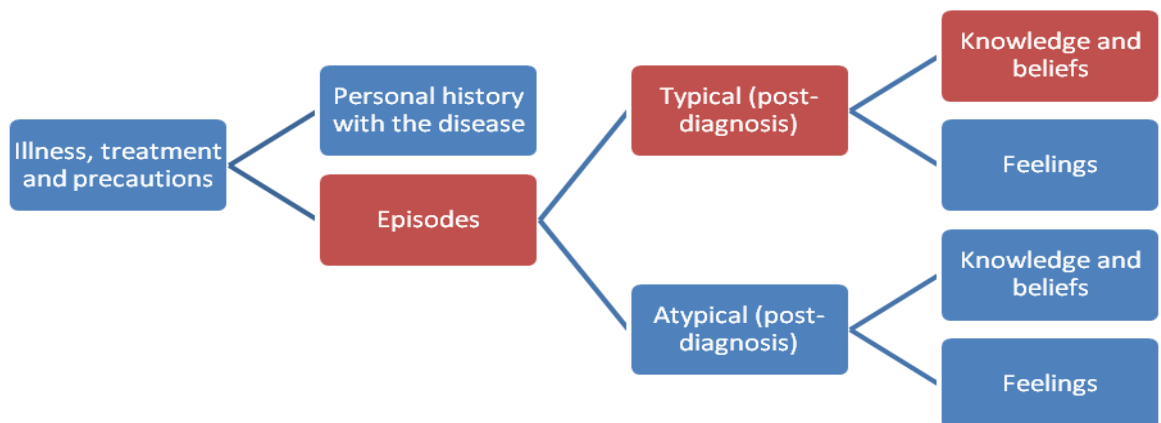
Respondent	Interview Extract
A_15	M: And you were always there (looks at child's grandmother) to hold his hand when he got a jab in his bum, because I wasn't. I: So that helped you quite a lot.

Feeling supported when distressed	<p>M: Yeah. (laughs)</p> <p>I: That your Mom was willing to do the hard bits in hospital.</p> <p>M: Yeah.</p> <p>I: So how did [child's name] respond to those kinds of experiences?</p> <p>M: Oh, he didn't like it, injections, but it didn't help that his mother was a blubbering idiot. So I'd sort of go and sob around the corner.</p>
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6.6.1. Summary of typical episodes – feelings

Parents reported feeling a range of emotions in association with typical episodes, including anxiety relating to the onset of attacks and difficulties in accessing medical attention quickly or easily. Even when such feelings were reported, they were not necessarily central to the parent report. For example, some parents expressed their feelings of frustration or anger relating to interactions with medical staff, sadness or disappointment for the child or for themselves, and discomfort. Most parents also reported positive or neutral feelings, often as part of the same event; for example, a parent felt distressed about their child having procedures involving needles, but felt grateful for family support at the same time.

6.7. ILLNESS, TREATMENT AND PRECAUTIONS: EPISODES – TYPICAL (POST-DIAGNOSIS) – KNOWLEDGE AND BELIEFS – DIABETES GROUP



The number and nature of typical episodes

Eleven parent or couples described episodes that were categorised as typical (D_1, D_3, D_4, D_6, D_7, D_9, D_10, D_13, D_14, D_15 and D_16). Further information may be found in Appendix 6.5. As in the asthma group, parents reported that these episodes occurred relatively frequently and that their characteristics and features were fairly predictable. In all but two cases (D_7, D_9), composite episodes were described (i.e. where two or more similar episodes were being described in a single episodic description). All episodes that were described related to a hypo or hyperglycaemic attack (all participants reported above).

Typical episodes – knowledge and beliefs

As with the asthma group, three kinds of knowledge and beliefs were expressed by parents:

- *Symptoms, treatment and causes in relation to the episode*
- *Risks and consequences of the episode*
- *Actions or behaviours of doctors, the child or other people in relation to the episode*

Symptoms, treatment and causes in relation to the episode

As indicated in Appendix 6.5, all eleven parents / couples referred in their description to their child's drugs, treatment or prevention of hypo or hyperglycaemic attacks, and all but one of these (D_3) indicated their knowledge of their child's symptoms and their significance. One couple expressed the view that their own child's difficult and angry behaviour was something that all parents of children with diabetes experienced (D_14). Several parents described how they made independent decisions without additional medical advice (D_4, D_10 and D_14), for example about whether the child actually needed hospital admission or not.

Some parents were less confident than others about their ability to maintain blood sugars within a normal range. One parent said she did not know how to get her child's blood sugars to an 'average' level (D_16), and two others said they had tried everything to manage or prevent future episodes, without success (D_1, D_14). One couple indicated that they didn't know how they were doing with the blood sugar control, as they had no comparison, but hoped that their child not being admitted to hospital indicated they were doing 'alright' (D_13).

Parents' views about causes or ways of preventing episodes varied. One felt the causes of episodes were external or unknown (D_3), and / or related to child-specific factors (D_3,

D_7, D_14) such as their non-compliance with treatment or entering puberty. Two parents expressed their belief that the prevention of episodes was possible through the parent's efforts (D_5, D_13); however the parents of D_13 also felt they were 'lucky' that their child didn't have many 'hypos'.

Beliefs about the consequences of abnormal blood glucose levels or the disease itself for the child or siblings were expressed by some parents. For example, the parent of D_1 believed repeated 'hypos' were bad for her child's health and development, the parent of D_15 felt that hospitalisation for poor blood glucose control was damaging for the sibling, and the parent of D_10 believed her son was more susceptible to other health problems because of diabetes.

Risks and consequences of the episode

Some parents experienced changed perspectives following episodes. For example, the parent of D_10 now feels she is waiting for something else adverse to happen. Other parents had increased confidence; the parent of D_3 is now more relaxed about using 'Hypostop' (now called Glucogel) when her daughter has a hypo and the parents of D_14 now feel more confident about going on holiday with their child immediately after hospitalisation.

Most of the above areas of knowledge and belief, risks and consequences of episodes are illustrated in the following excerpt, where the parents reported that their daughter had 1-2 'hypos' per week, and was frequently hospitalised:

Respondents	Interview Extract
<p>D_14</p> <p>Knowledge and beliefs about symptoms and treatment; changed perspectives following episodes</p>	<p>I: So, when was the last time [child's name] was ill, was it a while ago, or..?</p> <p>M: Last week.</p> <p>I: Just last week. She wasn't in hospital though?</p> <p>F: No. Callous indifference.</p> <p>M: Probably she should have done. But because we'd seen it before, we knew what to do.</p> <p>F: We knew what to do, i.e. do nothing, go and watch Richard and Judy on the telly. You know, go and do....</p> <p>M: She had no ketones. If she'd got ketones and she was being sick, well it's straight into [hospital ward's name]. But she was fine. If you can deal with it at home without having to go in there and have the hype...</p> <p>.....</p>

	<p>M: That time we went down to Cornwall, yes, you (looking at daughter) ended up in hospital the day we were supposed to go down there.</p> <p>F: And I mean that was funny. On the Sunday, we were due to go down. [child's mother's name] is cleaning the barn up on Sunday morning; we're due to go in the afternoon, and [child's name] has spent a night, a very pleasant night, on the [name of hospital ward] no big dramas. (Said very slowly) - And so on Sunday morning, I'd just gradually waft in - this is where the callous indifference comes along - waft into [name of hospital ward] at half past 9, 'nice to see you, just finishing off your breakfast?' 'Yes, she'll come home and she'll sleep, that's fine'. And we come back, and your Mom's been down and helped us rake out the barn and change all the sheets ready for the next lot, and 'yeah, that's fine'. And then, '[child's name], do you feel a bit sleepy? Well, go to sleep on the sofa'. (Said very quickly): And at 10 past 2, we're in the car, and off to Cornwall. 'And if you feel a bit sleepy, well you can just sleep in the car'. Callous indifference. Because what we would have done 18 months before is put the brakes on the whole bloody lot of it.</p> <p>M: Yeah, and not have gone.</p>
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Actions or behaviours of doctors, the child or other people in relation to the episode

Two parents (D_10 and D_14) expressed beliefs about doctors. The parents of D_10 and D_14 thought that doctors should provide more information about health problems, symptoms, risks and/or the recovery phase. The parent of D_10 also doubted the accuracy of a doctor's information (not one of the diabetes doctors). A couple (D_14) thought that doctors did not understand how difficult it was for parents to manage the child's blood sugar levels – and that the doctors 'had it easier' than the parents. They also felt that some doctors don't always recognise the seriousness of a situation when the parent does, and that parents just have to be assertive with doctors sometimes.

Four parents expressed their belief that others (teacher, other parent or sibling) were irresponsible or lacked knowledge of diabetes symptoms or management (D_1, D_7, D_9, D_10). Also, two parents thought that those who know the child well are best able to recognise a hypo (D_2, D_9).

Finally, five parents indicated whether they thought their child could or couldn't recognise and respond to signs of an impending hypoglycaemic attack, with four parents / couples saying they could (D_4, D_10, D_13, D_16), and one saying they couldn't (D_2). It is likely that parents who believe their child is more able to recognise the onset of symptoms will be less concerned to monitor their behaviour closely.

The following excerpt illustrates this aspect of knowledge and belief (about others):

Respondents	Interview Extract
<p>D_10</p> <p>Beliefs about teachers – lacking understanding</p>	<p>M: I sometimes might think, maybe they're [school] not really understanding that, or very understanding. Like we had a letter home that was saying he was actually eating. She said, 'I know that a diabetic may eat a couple of biscuits, but he's eating his whole, sort of baguette in the middle of the class or something, you know?' And I know that isn't right, but obviously I'd tend to make sort of more allowance for that. You know, he shouldn't be sat there eating his lunch in the middle of a lesson I suppose, but you tend to, oh well, think if he thought he needed it, then perhaps he does, you know? I'd rather give him the benefit of the doubt.</p> <p>I: So how did you resolve that?</p> <p>M: Well, I think [child's father's name] spoke to that teacher. He said, you know, I heard him say, 'Well, obviously if he's sat there eating his whole lunch, he shouldn't be doing that, but on the whole if he really feels he needs to eat, then give him the benefit of the doubt'. But we've never had where we've had bawling and complaining about anything. Working in a school, I know what children are, what they can be like, so it's not an easy job. So, if he was being a nuisance, then I'd rather know and try to deal with it. But I know, deep down, I'll tend to be on their heels a bit, (laughs), not feeling they're quite right.</p> <p>I: So, he's never had a hypo or anything at school, that you're aware of?</p> <p>M: Not a major one. He'll just have a well....</p> <p>I: He just recognises his symptoms himself and takes something to eat.</p> <p>M: Yeah. He's always got something in his bag. Yeah, he does. I've heard of others who get the signs so much more, and that must be awful. But...</p> <p>I: So he feels a bit light-headed or...?</p> <p>M: Yeah. Wobbly, and he always knows. If it happens in the night, it always wakes him up and he does call us.</p> <p>I: So if he wakes in the night, he calls you and you come in, and get him something to eat.</p> <p>M: Yeah. We always deal with it.</p> <p>I: So you don't really worry about him at night in that sense, when it happens at night.</p> <p>M: No, because I know. You know, I don't know whether that might change though. I do worry about him losing the ability to sense when he's going to go low, but that hasn't been a problem with him so far.</p>

6.7.1. Summary of typical episodes – knowledge and beliefs

Typical episodes described by parents related almost exclusively to the child's hypoglycaemia or hyperglycaemia. Most parents' descriptions indicated that they had accurate knowledge of their child's symptoms and treatment in these episodes. They also expressed beliefs about the negative consequences of their child's attacks for the child's health and development and for siblings; some parents considered positive consequences (e.g. that they were now more relaxed about using Hypostop).

However, parents varied in their levels of confidence in decision-making (e.g. how to control blood glucose well, when to take child to hospital, etc.). It did not necessarily follow that a parent who was knowledgeable about their child's symptoms and treatment was also confident in managing hypoglycaemic or hyperglycaemic episodes. For example, the parents of D_14 felt very knowledgeable and confident in how to respond during such episodes (e.g. whether the attack merited hospitalisation), but felt they had been unable to control their child's blood glucose levels well in general, despite their best efforts. On the other hand, two parents or couples whose child experienced few such episodes considered that the avoidance of these was related to their own efforts.

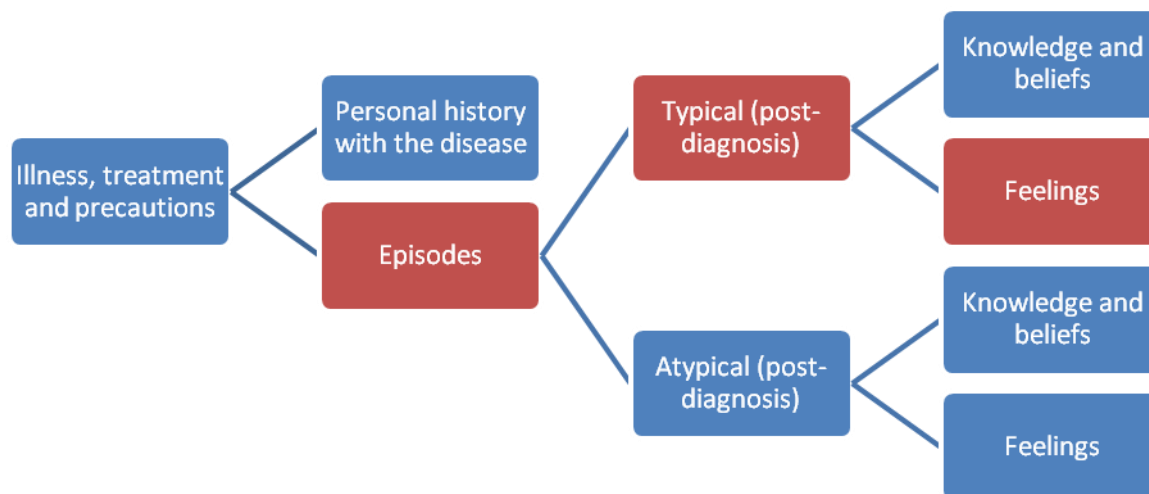
One reason for knowledgeable parents not always feeling confident in managing longer term blood glucose could be the parents' views about the illness (e.g. it is difficult to control and harder for parents than for the doctors, or easy to control). For example, the parents of D_14 felt they had done everything possible to control their child's blood glucose levels well, but without success; their child had 1-2 'hypos' every week, and frequent hospital admissions. In the interview, they stated that their child's blood glucose values tended to 'run high'. One reason why the parents may have had more difficulty in maintaining control was that they may not have had accurate records of their child's responses to treatment interventions. For example, the memory of blood glucose values in the child's blood glucose meter was not reliable as she sometimes tested her friends' blood. This would make it more difficult to alter treatment in response to symptoms.

In contrast, the parent of D_10 said her son only occasionally experienced mild 'hypos', and these were easily managed; he had only ever had one 'serious' hypo, which had required administration of Hypostop, and this did not result in hospitalisation. Therefore, although the experience of parents of D_14 possibly led them to know more about symptoms of abnormal blood glucose and how to respond in emergencies than the parent of D_10, they possibly had less knowledge about how to prevent these symptoms.

Another reason why knowledgeable parents might have lacked confidence could be child-specific factors that were mentioned by them as causes of the episode (e.g. child was non-compliant and ‘difficult’, child was entering puberty). Therefore, this meant that the parent felt less in control when trying to respond appropriately during such episodes.

Finally, a few parents expressed beliefs about others connected with the episode (doctors, teachers, another parent or the child), for example that doctors don’t always believe something is as serious as does the parent, or that doctors don’t provide enough information. More commonly, parents expressed beliefs that teachers, another parent or sibling were either irresponsible or lacked knowledge to respond appropriately (e.g. eating lunch before lunchtime, during class at school), or that the child did or didn’t recognise their own symptoms.

6.8 ILLNESS, TREATMENT AND PRECAUTIONS: EPISODES – TYPICAL (POST-DIAGNOSIS) – FEELINGS – DIABETES GROUP



The number and nature of typical episodes

Nine parents expressed their feelings in connection with typical episodes (D_1, D_3, D_4, D_6, D_9, D_10, D_13, D_14 and D_15). With one exception, which was of an episode unrelated to diabetes and which didn’t involve hospitalisation (D_10), all of these related to occasions when the child experienced very high or very low blood sugars (hyper or hypoglycaemia). In all but one example (one episode described by the parents of D_14)

typical episodes did not involve hospital admission connected with diabetes. Therefore, feelings were only described by parents in typical episodes where the parent, child and / or teachers were involved in managing (or some cases, not managing) the attack.

Most parents described feelings in connection with only one episode or composite episode (D_3, D_4, D_6, D_9, D_10, D_13 and D_15), two parents with two episodes (D_1 and D_10), and one couple who described 6 typical episodes (2 of which were composite episodes) (D_14).

Typical episodes – feelings

Four kinds of feelings were expressed by parents:

- *Worry, distress and anxious behaviours (expressed by 5 parents)*
- *Frustration, annoyance or anger (expressed by 5 parents)*
- *Uncertainty, lack of confidence / helplessness (expressed by 3 parents)*
- *Positive and neutral feelings (expressed by 7 parents)*

Worry, distress and anxious behaviours (expressed by 5 parents)

The parents who expressed these kinds of feelings were worried or distressed by different sorts of things. Two parents / couples talked about distress or worry that was related to the events surrounding the episode (a severe ‘hypo’). For example, the parents of D_4 both found it distressing to have to force glucose gel into their child’s mouth during severe hypos, but the father sometimes found that he couldn’t deal with these situations at all, which he believed was related to other stressors in his life (e.g. trying to get his own business off the ground). Another parent (D_1) found her child’s response to procedures involving needles distressing, and was upset that she couldn’t reveal her own upset to her child.

Three parents express worries related to the future; sometimes these worries seem to have arisen from the parent trying to make sense of episodes, perhaps involving cognitive restructuring. For example, the parent of D_10 said that she thought her child had more illnesses than other children (such as getting whooping cough due to immune system weakness, and problems relating to moles), which she thought might be due to the diabetes. Therefore, she worried about her son’s future health and was suspicious that diabetes doctors didn’t always tell parents everything that could go wrong. Also, she was aware from her interactions with other parents of diabetic children (being an active member of a support

group for diabetic parents) that other children didn't recognise early signs of 'hypos', whereas her child did; she was concerned that her son could lose the ability to recognise hypos (as indicated at the end of the excerpt in the previous section, under '*Actions or behaviours of doctors, the child or other people in relation to the episode*').

Another parent (D_3) said she had felt ill at ease before the first serious 'hypo', as she didn't know what would happen. However, after experiencing several episodes of her child having a 'hypo' at school during PE, she became worried about who would deal with a hypo and look after her child when she was separated from her. This parent discussed how she and her husband did not ever go away for a weekend or short break together, as they were too worried about their child having a severe 'hypo'. Finally, one parent (D_15) expressed worry about the potential effect on the child's sibling, should her son have a hospital admission.

It was interesting to note that the parents who reported the highest number of typical episodes (D_14) did not report any worries, distress or anxious behaviours connected with these episodes. Perhaps this was because the episodes were so frequent and ordinary for them, that they had normalised these episodes and were less worried about them over time. Alternatively, they might well have felt worried or anxious, but other feelings predominated so they did not report them.

Frustration, annoyance or anger (expressed by 5 parents)

Although one parent said she was annoyed at herself if the child had a 'hypo', because she thought it was her fault (D_4), the frustration, annoyance or anger expressed was directed at others – doctors, teachers and sometimes the child. Some parents felt angry at or annoyed with the child for withholding health information (D_4 and D_14), with one couple also feeling frustrated at their lack of success in persuading the child to be compliant (D_14). However, most commonly, parents expressed anger or annoyance with teachers for not preventing or responding to their child's 'hypos' (D_1, D_3, D_9 and D_14). Parents felt that some teachers and doctors lacked understanding (D_9 and D_14). It is likely that many teachers will not previously have encountered children with diabetes in their classes, and may lack opportunities for education. Future research may be valuable to investigate this question further.

The following excerpt illustrates the common finding that parents were angry, or in this case, annoyed with teachers in the context of typical episodes:

Respondent	Interview Extract
<p>D_9</p> <p>Parent annoyance at teacher for not responding to attack, lacking understanding</p>	<p>M: There's still a lot of teachers that don't understand, and there was a maths teacher. [Child's name] doesn't like maths anyway so it could have been an excuse, but she was actually going low in lessons, and a friend recognised it, and said, 'Oh, are you alright [child's name]?' So, he came to the desk, and said, '[Child's name's] going low'. He said, 'Well, I don't know what that means'. So he said, 'Well she's got diabetes'. 'Well she can go low after she's finished the maths exercise'. And I wanted to phone up, you see. And 'No, no', not to phone up you see, because they don't want you to. It's just that.</p> <p>I: [child's name] didn't want you to phone up?</p> <p>M: No. I was going to phone and say, 'Look, do you think you could just have a word?' and I'm sure he just thought, 'So what, somebody's not well.' I guess he didn't know, but you feel as though they should be more aware, I suppose.</p>

Uncertainty, lack of confidence / helplessness (expressed by 3 parents)

As in the last section, the issues about which parents lacked confidence varied, and this was mostly expressed by one couple (parents of D_14), as shown in the next extract. Of the two other parents, one father felt unable to handle his child's 'hypos' because of his own problems (D_4) and one parent felt clinic staff were more competent than she was in calming her child when he was having needles (D_1).

The extract below shows how feelings of helplessness were felt in relation to both managing the child's behaviour and responding to teachers' apparent lack of proper medical care. Although the final part of this extract reflects the perspective of these parents about the teachers' behaviour, there could be some debate about what is and is not the proper role of the school and teachers in such situations:

Respondent	Interview Extract
<p>D_14</p> <p>Feeling helpless and uncertain</p>	<p><i>This section relates to parents' feelings about their inability to discourage their child from non-compliance that often led to a hospital admission, by making her hospital stay more unpleasant (i.e. threats about asking for the IV to be put in the right hand when she was right-handed, so she couldn't do craft activities):</i></p> <p>F: And the trouble is, the ultimate threat from Mommy to [child's name] when [child's name's] being obstreperous is '[child's name], which hand do you want it in this time?' Yeah. And the reason why she wants it in the right hand is..?</p>

M: Because [ward's name] are very good at giving her all bits of drawing and craft bits to keep her moving and happy in there. Well if she's got it in her right hand, she can't do it.

C: I can still do it.

M: Hopefully, it will encourage her not to go into [ward's name].

F: Which hand do you want it in, [child's name]?

C: Right. (laughs)

F: As I say, I hope you're getting the idea that we have tried everything.

The next section refers to helplessness in relating to relating to the child's lack of communication about her health care:

M: Now because [child's name] was coming home with high blood sugars, and we weren't being aware of why she had got a high blood sugar; [child's name] then says, 'I don't know'. And it's because [child's name] had had a hypo at school, had had some Lucozade, and so naturally it was high. But [child's name] wouldn't tell us that.

F: Because I suppose she thought she was going to get a rollicking when she came home.

I: For letting herself go hypo?

F: For letting herself go low. And the trouble is, again, its very difficult as a parent, do you say nothing, and wait to be told, or if you're on somebody's case all the time, they're not going to tell you.

This final section refers to an incident where the child had been on a school trip, and teachers had not recognised that her sleeping on the way home on the bus could have been due to the child losing consciousness:

I: So was [child's name] OK with that, or was she difficult to rouse?

M: Fortunately, she'd been on the scoff and she'd been eating unbeknown.. Maltasers.. And so she was very high.

F: Laughs.

M: Which it could have been worse anyway, but because [child's name] likes running at about 24, you know, it's fine. [N.B. '24' refers to blood sugar, of which the normal range is 4-8 mmol/l]. [Child's name's] body is used to running very high, so she's used to that. And so it was perfectly OK. But it could have been a very difficult situation. But you can't have a go at the school about it, but because I work in the school I just...

F: You didn't then.

	<p>M: I didn't then, but I was working at pre-school then.</p> <p>F: You can't go and alienate the school.</p> <p>M: You can't tell them off but then again they do have to be aware, you know.</p> <p>I: It's a difficult dilemma for you then really?</p> <p>M: Yes.</p>
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Positive and neutral feelings (expressed by 7 parents)

Some parents expressed how they tried to look at the positive side of the experience of these episodes in terms of learning. For example some described the confidence gained in managing episodes so that effects are not too influential on life (D_10, D_14), or that going through the negative experience was necessary and that there was a positive side in terms of personal learning (D_3).

Being accepting of others' or own feelings and behaviour, or valuing others' acceptance was also expressed. This included accepting the child's need to express anger (D_14), acknowledging that the parent needed to express their own anger (D_3), and feeling that the child was brave when having needles and was accepting of his diabetes (D_1). Parents also were accepting of teachers, saying that they couldn't be expected to always respond appropriately as they didn't know as much as the parents did (D_3, D_9).

Some parents compared themselves positively with hypothetical others or hypothetical situations. For example, the parents of D_14 said they thought that other parents experience similar difficulties; similarly, the parents of D_13 and D_15 felt positive because their child hadn't been in hospital since diagnosis, believing this showed less good control in other children. One couple reminded themselves that a bad situation could have been worse (D_14).

It was noted that as with the asthma group, parents who expressed confidence or positive feelings also expressed other emotions referred to earlier. No parent only expressed positive feelings.

6.8.1. Summary of typical episodes – feelings

Parents expressed a range of emotions when describing typical episodes, which mainly related to those where the child was experiencing symptoms of ‘hypos’. Some expressed worry, anxiety or distress about the event and future hypothetical events. Others described their feelings about others not meeting their expectations during the episode; this led to feelings of expressed frustration, annoyance or anger at teachers, doctors or the child. Helplessness and uncertainty were occasionally expressed by parents who felt they were unable to manage such episodes.

However, positive and neutral feelings were reported by nearly all parents, all of whom had also expressed feelings in one or more of the other areas. Many parents tried to look at the positive side of the episodes in terms of their own learning. Others were accepting or valuing the acceptance of others.

Therefore, overall, whilst parents did report a range of negative emotions related to typical episodes, they also seemed to try to see the positive side or report feelings of increased confidence or valuing of others.

6.9 ILLNESS, TREATMENT AND PRECAUTIONS: KNOWLEDGE, BELIEFS AND FEELINGS IN TYPICAL EPISODES - COMPARISON OF ASTHMA AND DIABETES GROUPS

Knowledge and beliefs

In both groups, most parents described typical episodes in which they expressed beliefs and knowledge relating to their child’s illness, its treatment and prevention / precautions.

For the asthma group, a wider range of episodes was described, including those connected with prevention of or avoidance of asthma attacks as well as responses during asthma attacks.

Nearly all of the episodes described by parents in the diabetes group related to the child’s hypoglycaemia or hyperglycaemia. Only one couple (D_14) described typical episodes involving hospitalisation, whereas for the asthma group, such accounts were more common.

Although composite episodes were described by both groups of parents, only 3 parents described composite episodes in the asthma group, whereas most parents did so in the diabetes group.

This seems to be because for the asthma group, the nature and circumstances of the episodes varied more than in the diabetes group. For example, some parents in the asthma group talked both about episodes relating to preventing attacks and managing them; furthermore, the attacks described sometimes had different outcomes, with some being managed at home and others at hospital. Also, circumstances preceding a hospital admission varied; for example, the parent of A_5 described an occasion when her son was hospitalised following touching a horse and another when she had done his peak flow and found it very low, so took him straight to hospital. In the diabetes group, there tended to be much more similarity in the episodes described across the sample. Most of these parents described ‘hypo’ episodes where these were managed at home. There was only one exception (D_14) where hospitalisation episodes were typical. Therefore, for the diabetes group, the onset, features and management of typical episodes had a more predictable and consistent pattern than in the asthma group.

The following table summarises the kinds of knowledge or belief expressed by parents in the context of their description of these typical episodes. These are discussed below more fully.

Table 6.1: Comparison of the most common examples of knowledge and belief across the two groups

Kinds of knowledge and / or belief	Group where this was expressed	Always, frequently or rarely reported	Most common examples
Symptoms, treatment and causes	both groups (not prevention in diabetes group)	<i>Asthma group</i> – Frequently (9/10 parents / couples) <i>Diabetes group</i> - Frequently (7/11 parents / couples)	Drug choices and dosages Prevention measures Recognising and treating hypos
Risks and consequences of episode	both groups	<i>Asthma group</i> – Rarely (2/10 parents) <i>Diabetes group</i> - Rarely (4/11 parents / couples)	Hospitalisation has an infection risk for child Changed perspectives (negative or positive) affecting beliefs or behaviour
Knowledge and beliefs about doctors, child or other people	both groups	<i>Asthma group</i> – Frequently (7/10 parents) <i>Diabetes group</i> - Frequently (9/11 parents / couples)	Parent is often more competent than doctor in assessment and treatment, and doctors should appreciate parents’ experience more Teacher, other parent or sibling are irresponsible or lack knowledge in diabetes care

It is interesting that parents in the diabetes group did not describe episodes relating to prevention, considering this is a key focus of disease management. This could be because preventing ‘hypos’ is linked to a complex interaction of everyday diabetes management of insulin, blood glucose testing, diet and exercise; furthermore, it is not always obvious what specific set of behaviours (e.g. had too much exercise and not enough food) led to a ‘hypo’ that parents would be able to pinpoint in their descriptions. For this reason, these preventive behaviours might not have stood out for these parents as the focus of episodes, unlike in the asthma group where preventive episodes tended to include clear cause-effect descriptions. Furthermore, in contrast to children with diabetes, parent of asthmatic children often described causes and effects that were closely temporally-linked, and the effect was often both immediate and observable (e.g. exposure to pet dander resulted in asthma attack). This is likely to have strengthened the parents’ perception of these cause-effect relationships, leading to greater reference to them in their descriptions.

Finally, parents of asthmatic children, unlike those with diabetic children, often took very specific steps that were linked to unique circumstances, to avoid an attack. For example, the parent and child of A_1 left a party early because there was cat hair on the furniture. Thus, the consistency and regularity of preventive behaviours and lack of obvious single, tightly temporally-linked cause-effect relationships between a preventive behaviour and blood glucose fluctuations could explain this observation. It is possible that the parents of diabetic children might therefore experience less self-efficacy in relation to preventive behaviour due to lack of awareness of precise causes and therefore the potential effects of blood glucose abnormalities (which also are not directly observable).

For both groups, three kinds of knowledge and beliefs were expressed:

- Symptoms, treatment and causes in relation to the episode
- Risks and consequences of the episode
- Actions or behaviours of doctors, the child or other people in relation to the episode

Symptoms, treatment and causes in relation to the episode

In both groups, parents expressed beliefs and a high degree of knowledge about their child’s symptoms and treatment management, for example being able to make independent decisions about treatment interventions (e.g. whether or not their child should be taken to hospital, or

how to alter a drug dosage). Some parents in the diabetes group however felt they did not know how to get blood sugars 'average' or did not know what else to do to manage their child's blood sugars more effectively (D_1, D_14 and D_16). Therefore, although these parents were knowledgeable about their child's symptoms and treatment, they lacked confidence in controlling their child's blood glucose. As stated previously, the particular complexity of diabetes management could be a factor accounting for this.

Parents in both groups speculated about or inferred causes of episodes. Both groups of parents identified child-specific factors as causes; for example, the parent of A_14 thought an asthmatic attack was partly due to their child's excitement about being on holiday, and the parent of D_3 that unstable blood glucose was because her daughter was entering puberty. No parents in the asthma group reported causes of episodes or the outcomes of episodes as being due to their own actions, whilst two parents of the diabetes group believed that the avoidance (D_13) or occurrence (D_6) of an episode was due to their own behaviour. Possibly the parents in the asthmatic group did recognise the role of their own actions (because they described early symptoms and so on, and the actions they took as a consequence), but their views about their own influence on outcomes of the episode were not explicitly stated.

Parents in both groups also identified external causes of the episodes. For the diabetes group, these related to the degree of blood glucose control, i.e. partly due to good luck or bad luck (D_3, D_13), although in neither case was this considered the only reason. In the asthma group, external causes were also among those discussed by parents; these related to the weather, a food allergy or exercise (A_8, A_12 and A_14). It could be significant that the latter might be more controllable (i.e. one could avoid certain foods or not go outside in certain weather) but good and bad luck is not something one can control. Therefore parents who thought at least an element of their child's episode was due to good or bad luck (i.e. D_3 and D_13), might under-estimate the effect of their own actions (as was the case of the parents of D_13, who stated that they didn't know if they were doing well or not in controlling their child's blood glucose). Interestingly, these parents had the most recently diagnosed child, so this could be a factor influencing their response in this area.

Risks and consequences of the episode

It was only in the asthma group that parents discussed balancing risks and consequences in relation to preventive health behaviour. Parents balanced their child's medical needs and risks against benefits for their child's psychological or social wellbeing. Sometimes parental

decisions differed from the 'received' medical recommendations to avoid risks. The reason this aspect of knowledge and beliefs did not arise in accounts of typical episodes of parents of diabetic children was probably because, as discussed earlier, preventive health behaviours did not feature in the types of typical episodes described by this group of parents.

However, parents of both groups expressed beliefs about the negative consequences of their child's attacks (whether asthmatic attacks or blood glucose aberrations) for the health or wellbeing of the child or sibling; some parents considered positive consequences.

Some parents in the diabetes group highlighted consequences for themselves as outcomes of episodes, in terms of changed perspectives or changed behaviour. It's possible that this is because most diabetic children in the sample had not been diagnosed for as long as those in the asthma group; the parents of children with asthma might well have experienced such changed perspectives or behaviours many years previously. For example, the parent of D_3 described typical episodes of her daughter having a 'hypo' at school, but her learning / changed perspective related to the first occasion when glucose gel was used. Equivalent typical episodes were not described for the asthma group. This point will be of interest when discussing the next theme, 'feelings over time'.

Actions or behaviours of doctors, the child or other people in relation to the episode

Some parents in both groups expressed views that some doctors did not fully appreciate and acknowledge the parents' competence or concerns and / or provide enough information. Parents sometimes believed that doctors did not always know what was best for their child, or fully appreciate the parents' experience and knowledge. This was particularly evident in the asthma group. Possibly this was because many of these parents had been managing their child's asthma (and sometimes that of siblings) for many years as most children with asthma were diagnosed about aged 2 years. However, this was not necessarily parents' views of all doctors, some of whom were deemed very competent, and it was viewed that one had to trust them.

In both groups, parents sometimes expressed beliefs that teachers, another parent or sibling were either irresponsible or lacked knowledge to respond appropriately when the child had an attack. A number of parents discussed their child's ability to act appropriately on assessing certain situations. In the case of the diabetic children, parents discussed how their child could or couldn't recognise and respond to an impending 'hypo', whereas in the asthma group a comment was made that the child could or couldn't assess and respond to risky situations.

Overall summary about knowledge and beliefs

In short, there were many similarities across the two groups in terms of areas of knowledge and belief expressed. However, whilst in both groups parents reported knowledge and beliefs in the context of acute episodes (e.g. asthma attack or ‘hypo’), those in the asthma group described a wider range of acute situations (such as whether or not the child was hospitalised), and also preventive episodes. This may account for why more ‘composite’ episodes were described by parents of diabetic children.

Whilst parents in both groups expressed a high degree of knowledge about symptoms and treatment, a small number of parents in the diabetes group continued to lack confidence about management. It is possible that if parents of diabetic children viewed positive outcomes of episodes as being due to luck (or negative outcomes due to bad luck), this could diminish their beliefs that good blood glucose control is due to their own efforts. Parents in both groups described their beliefs about both external and child-specific causes of episodes.

Balancing risks and consequences in the context of episodes involving preventive behaviour was described by some parents in the asthma group but not the diabetes group. However, both groups of parents described their beliefs about the consequences of repetitions of the episodes (e.g. ‘hypos’ or hospitalisations). Only in the diabetes group did parents describe consequences for themselves in terms of new learning or changed behaviour; this could be due to the fact that most of the children in this group had been diagnosed more recently than those in the asthmatic group, so new features of typical episodes were still being experienced. Alternatively, the complexity of typical episodes in the diabetes group could mean that parents had more to learn.

Finally, both groups of parents expressed beliefs about doctors, the child and others. Most of these were connected with the belief that sometimes doctors did not adequately appreciate or acknowledge the parents’ knowledge and experience. Views about teachers were also expressed by both groups, such as believing them to lack knowledge about responding to the child’s health needs. Also, views about the child’s competence to recognise symptoms or recognise risky situations were expressed by parents in both groups.

Feelings

In both groups, parents reported feeling a range of emotions in association with typical episodes, as expressed in the following table, which also shows similarities and differences:

Table 6.2: Comparison of the most common examples of feelings across the two groups

Kinds of feelings	Group where this was expressed	Always, frequently or rarely reported	Most common example
worry, distress and anxious behaviours	both groups	<i>Asthma group</i> - Always (9/9 parents / couples) <i>Diabetes group</i> - Frequent (5/9 parents / couples)	Linked to ‘here and now’ of episode - not being able to get medical attention in time. Linked to after episode - worries about the future (e.g. who will deal with future attack)
frustration, annoyance or anger	both groups	<i>Asthma group</i> Frequently (5/9 parents / couples) <i>Diabetes group</i> Frequently (5/9 parents / couples)	Annoyance with doctors for not focusing on immediate, or where doctor disagrees with them. Annoyance at teachers for not responding adequately in risky situations.
positive and neutral feelings	both groups	<i>Asthma group</i> Frequently (7/9 parents / couples) <i>Diabetes group</i> Frequently (7/9 parents / couples)	Feeling confident about avoiding attacks. Accepting others (e.g. teachers can’t be expected to know everything; accepting child’s anger)
uncertainty / lack of confidence / helplessness	diabetes group	<i>Diabetes group</i> Rarely (3/9 parents)	Feelings of helplessness about how to deal with other’s behaviour (child, teachers)
sadness and disappointment	asthma group	<i>Asthma group</i> Frequently (5/9 parents)	Feeling sad for own child (enduring disappointments, enduring hospital experiences)
discomfort	asthma group	<i>Asthma group</i> Rarely (3/9 parents)	Discomfort in hospital setting (sleeping or bathing arrangements)

The above table shows that all parents in both groups experienced worry, distress and anxious behaviours. However, the nature of the worries differed – parents in the asthma group tended to worry most about accessing medical attention quickly or easily (i.e. an aspect of the episode itself), whereas parents in the diabetes group worried most about the future. This could be because many of the urgent episodes described by parents in the asthma group were

potentially life-threatening in a short space of time for the child. For the children in the diabetes group, whilst episodes could be life-threatening, normally medical intervention occurs well before this point would occur.

Similarly, although parents in both groups expressed frustration and annoyance, parents in the asthmatic group tended to direct these feelings more towards doctors, whereas parents in the diabetes group directed them more towards teachers. One possible reason is that the care of many children with asthma was managed by local GPs (and in some cases Accident and Emergency Department doctors), many of whom did not know the child; in some cases parents felt they lacked detailed expert knowledge. This led to parent frustration when the doctor seemed to not be responding how they thought they should. Also, most of the children in the asthma group were not followed by a specialist community children's nurse, as was the case with the diabetes group, so they would have had less specialist support in general.

In contrast, the children in the diabetes group were followed regularly by the same clinic doctors and had a specialist children's community nurse to call on when needed. The stronger frustration of diabetic group parents directed at teachers in the context of typical episodes could be because teachers may be more familiar with asthma management than diabetes management, as it is a more commonly experienced health problem in school children.

Also, the children with diabetes were less able to take full responsibility than asthmatic children for their treatment, which would put a greater onus on teachers during the day, leading to a greater potential for reduced support. Although positive feelings about teachers were expressed by parents of children with diabetes, these were not in the context of descriptions of typical episodes. Further information about relationships with school staff in general is included in the next chapter.

The most commonly expressed positive or neutral feelings were unsurprisingly associated with the most common kinds of episodes described. Parents of asthmatic children who reported frustration with doctors during acute episodes also felt positive about their own ability to manage them. Some parents of diabetic children who felt frustrated with teachers also felt a level of understanding and acceptance that teachers can't know as much as the parent does.

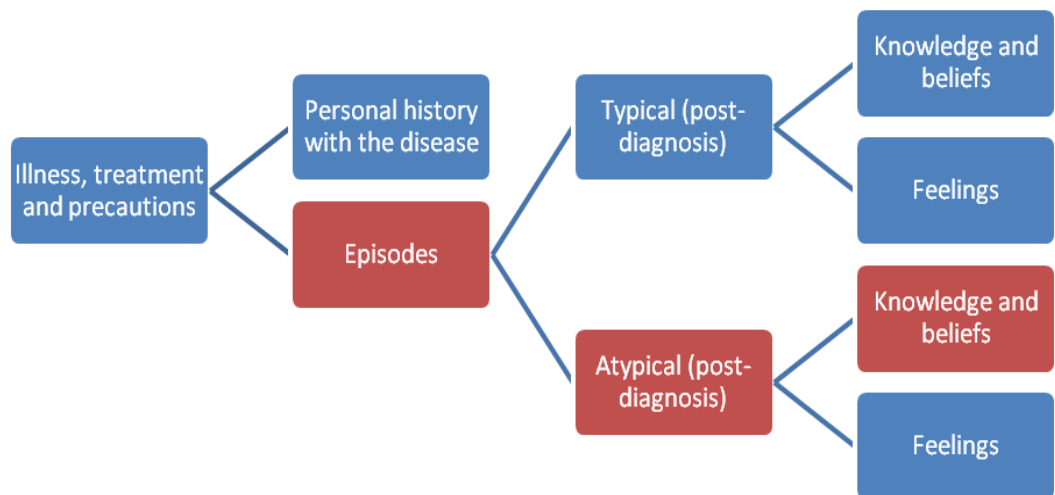
Feelings of sadness and disappointment and discomfort, which were only reported by parents in the asthma group, were frequently connected with acute episodes, usually involving

hospitalisation (which was described by parents of only one diabetic child) or with preventive episodes (also not described by parents in the diabetes group).

Overall summary about feelings

Therefore, overall, whilst parents did report a range of negative emotions related to typical episodes, they also seemed to try to see the positive side or report feelings of increased confidence or valuing of others.

6.10 ILLNESS, TREATMENT AND PRECAUTIONS: EPISODES – ATYPICAL (POST-DIAGNOSIS) – KNOWLEDGE AND BELIEFS – ASTHMA GROUP



The final sub-theme to be discussed relates to atypical health episodes (mostly relating to the child’s asthma attacks). These are ones that occurred only once or infrequently, and with symptoms that parents did not expect from prior experience (i.e. were atypical). As with the typical episodes, this sub-theme does not include those episodes that led up to a diagnosis, as these were coded under the theme of ‘Feelings over time’.

The number and nature of atypical episodes

Twelve parents or couples described knowledge and beliefs in the context of episodes that were categorised as atypical (A_1, A_2, A_3, A_5, A_6, A_7 A_8, A_9, A_11, A_12 A_15

and A_16). Further information may be found in Appendix 6.7. Most of these episodes related to acute hospital admissions for an asthma attack. Unsurprisingly, unlike in typical episodes, only unique (i.e. not composite) episodes were described.

Three kinds of atypical episodes connected with the child’s chronic illness were described:

- *Acute attack involving hospital admission (9 parents / couples)*
- *Medication administration issue (2 parents)*
- *Encounters with doctors (health visits for asthma or eczema) (2 parents)*

Parents described their knowledge and beliefs in somewhat more detail than they did in typical episodes, possibly because these stood out for them in a more striking way. Within their descriptions, parents expressed knowledge and beliefs about the following two areas:

- *Symptoms, treatment and / or causes in relation to episode (expressed by all parents)*
- *Knowledge and beliefs about doctors (expressed by 6 parents)*

Symptoms, treatment and causes in relation to episode (expressed by all parents)

A striking feature of parents’ descriptions of knowledge and beliefs in relation to acute attacks was that these were often time-linked. For example, parents often described their initial knowledge or beliefs such as about the meaning of early symptoms of an attack; then they tended to describe their beliefs during the episode about causes; finally, they tended to describe new knowledge or beliefs, and how this affected their subsequent decision-making, attitudes or beliefs. Parents also expressed knowledge about symptoms or drugs and treatment in general, which was not time-linked.

The following illustration shows this time-linked nature of acute asthma attacks that was commonly expressed by parents:

Respondent	Interview Extract
A_7	<p>I: You were saying she had one hospital admission where she went quite blue, you were saying earlier.</p> <p>M: Yeah, that was back, not last year - because we moved in here in July - it was the year before. She went in in June, July and September.</p> <p>I: June, July and September, in the same year?</p> <p>M: Yup. The same year, we had 3 admissions in - one a month.</p> <p>I: Oh dear.</p>

<p>Changes in knowledge and beliefs as a result of the episode has led to different parent treatment management behaviour</p>	<p>M: And it was one of them where she went quite blue ‘round her eyes, and like all ‘round her mouth, and her oxygen level, her sats, were quite low when we got in, so she had to sit with an oxygen mask on. Then pepped that up, and then the nebuliser, then go back to the oxygen again. So, that was really frightening, that was. ‘Cause the paramedics had to take her in in the middle of the night, which frightened [child’s name] even more - these people in green suits coming to take her in....</p> <p>Yeah, that was the last time she went in, ‘cause now I tend to - if I notice she’s having her inhalers more and more, I then tend to take her to my GP. Try and catch it early, if there’s going to be a chest infection, which then we rapidly increase - I increase the inhalers on my own accord. Then I go up for steroids and antibiotics from him. She’d be on a course of them for 7 to 10 days, and then hopefully you get a bit of improvement.</p>
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Other parents discussed whether or not they recognised early symptoms that were related to the onset of or recovery from an asthma attack or other symptom-linked episode, such as in the case of the child of A_5, who took too much of his steroid drug, because he thought this would help him play football better. His mother recognised the symptoms of the steroid drug overdose and intervened to stop him continuing this.

Some parents recognised early symptoms of an asthma attack, even when they were unusual, as in the case of A_12, where the child had been frequently hospitalised but previously had not had the observed symptoms in this incident.

Respondent	Interview Extract
<p>A_12</p> <p>Recognising atypical signs of an impending asthma attack</p>	<p>M: I mean like the last time he went into hospital, [doctor’s name] said to me...I’d slept on [child’s name’s] floor. And [doctor’s name] said, ‘Why did you sleep on his floor? Why did you stay in his room? What was it?’ And I said, ‘I don’t know, because there was no wheeze, and the was no cough, and that worried me, because he had been wheezing and coughing in the day, and I’d given him medication, and it seemed to have stopped the wheeze and stopped the cough, which are the signs you look for as a mother. So, the medication had worked. There was no noise in the airways. And I said, ‘And that worried me. That worried me that you could go from a lot of, a lot of you know three signs, you know with recession, go to that, medicate, and go to no noise’. So I said, ‘It just didn’t feel right to me. No noise didn’t feel right. So I slept on his floor. And I actually rang the ambulance and I said to the ambulance, ‘You know, I think I’m mad, but I’m calling you because I think he’s deteriorating in his sleep and there’s no noise in the airways’. And the Doctor said, ‘You did the right thing’. He’d gone past that point of whatever. And you just think, ‘Gee....it would have been so easy to think, ‘Oh, he’s better’, and had gone back to bed. You know, and said, ‘Oh, there’s no noise’. And he probably wouldn’t have been here.</p>

	<p><i>The parent went on to describe some of the effects of the episode, including the following:</i></p> <p>All of this year [following this episode], I've had an enormous respect for asthma, and we've gone to the hospital early, and you know how you are with children, your senses are really prickled, aren't they? You're sort of listening for every noise or change. So I've been more sort of acute.'</p>
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Other parents did not recognise early symptoms if they were unusual for that child, as was the case with the parent of A_3, who did not recognise that her child's irritable behaviour was not just adolescent 'stoppiness':

Respondent	Interview Extract
<p>A_3</p> <p>Adolescent girl</p> <p>Not recognising an impending asthma attack</p>	<p>M: She'd had, as a baby, she'd had her wheezy spells, especially when she got a cold, and I don't actually remember what triggered the big one off. She was quite irritable, and apparently that's a sign. So now, I sort of think, if she's really stropky, is she having an asthma attack? Because I'm aware of that now. Now I know what happens. But bearing in mind I left home that day just to get her checked out....</p> <p>I: Because she'd started having some symptoms, or..?</p> <p>M: She'd been sort of peculiar all day. But she is a very stropky teenager, and I didn't recognise the symptoms, and I think about, I don't know, about six o'clock, I said, 'Right. I shall take you the hospital to have you checked out!' That's what we went for. And by the time I'd got, I suppose I live in [name of town], and [name of second town] would be about, oh, not very far, eight miles away, and she stopped breathing at that point. Apparently, you're supposed to call the paramedics. I just thought I was quicker taking her there, but I very nearly didn't make it. So, we're very lucky. She was very fortunate to survive. But as I say, touch wood, we're OK.</p>

A_3 above is also an illustration of how sometimes parents described their beliefs about causes of the incident at the time. This parent believed that the attack had been precipitated by the child having stopped taking her asthma medication (on the incorrect advice of the asthma nurse at their local health centre). Therefore, she is now very rigorous about ensuring her daughter takes her medication.

In all of the above acute episodes, as was often the case following such circumstances, parents described how their perspectives and / or behaviour changed as a result of the incident. For example, A_7 realised after the last hospital admission that she could do more in terms of drug management and pre-emptive visits to the GP to prevent her child's symptoms from escalating, thus avoiding future hospital admissions. The parents of A_12 and A_3, whose child had experienced a life-threatening asthma attack, were now more alert and responsive to the child's unusual symptoms and also had a greater awareness of their child's possible death.

The point made about the increased awareness of the child's possible death also impacted on the beliefs and behaviour of the father of A_12 (according to the mother), who following this episode has refused to go away from the area for a holiday. Three other parents (A_7, A_9 and A_15) reported how learning from the episode helped them to better predict potential health problems and / or resulted in them changing their actual or anticipated future behaviours.

Knowledge and beliefs about doctors (expressed by 6 parents)

Six parents / couples discussed knowledge or beliefs about doctors following the episode. The beliefs were categorised as follows:

- *Doctors don't always know what's best for the child; they might not appreciate the urgency of the situation or they don't agree with the parent's view (expressed by 6 parents)*
- *Doctors can't answer all the parent's questions (expressed by 1 parent)*
- *Doctors appreciate that the parent responds correctly during an attack (2 parents)*

The first point above was the most commonly expressed, and the following example (A_16) illustrates the first two points above. This parent had a medical science background:

Respondent	Interview Extract
<p>A_16</p> <p>Good doctors respect and listen to you</p>	<p><i>Meeting a new doctor at the respiratory clinic to which child had just been referred:</i></p> <p>M: Yes, he [doctor] really listens to you. Because most of them, they patronise you. They don't. So, he did sort of listen. He seemed to understand the way we work, because I think they have sort of a lot of research people there. He didn't talk to us like he was talking to somebody who doesn't know anything of what they're talking about. Sometimes they think parents just get information from the internet, and want to interfere with what they do. We're not trying to, we're just trying to discuss. He wasn't, he was really nice, he talked and he gave you time, so I really liked him. He's really good.</p> <p><i>Parent had just been talking about more negative experiences at a different hospital closer to where they live:</i></p> <p>I: Because that's very frustrating, isn't it, to feel like nobody really has an understanding of the whole picture really, it seems.</p> <p>M: Yes, like we just left [during the last hospital admission] and how are we going to do now? We have to keep asking, 'How many breathing is</p>

<p>Doctors should focus more on the urgency of the situation with a sick child, and less on rules</p>	<p>the threshold when we can come back here?’ You know, they don’t seem to tell you. We are told forty, or ‘Oh, forty’s too high, you should have come earlier’. I will say one thing. Once we went to this ward that was meant to be a children’s ward, but emergency for children’s ward, so we went there straight away, because he was really bad. They said, ‘Oh, we’re going to deal with you now, but you shouldn’t have come here. You should have gone to A&E’, and we were worried because if we go to A&E, we might have to wait for ages, so we didn’t know. And we were told by the GP, ‘Go straight to this ward’. We went, and they said, ‘It’s the last time we’re going to deal with you here’. God! Your child is terrible, and they tell you off! So you just feel, ‘What are you going to do?’ Yes, horrible, isn’t it?</p> <p>I: So frustrating.</p> <p>M: Frustrating. Where do you go? Go to A&E? No. Go to the children’s ward A&E? Now he said I should have gone to the other one. Under those circumstances, you don’t want to hear those things. You want them to deal with the case. You know? So that is really frustrating. So that’s why we’ll do anything to not get there. But we need to go there. (Laughs). But at the [other more distant hospital] we never had any, I mean, [child’s name] hasn’t been there when he had asthma, but they seem to be taking a different approach there. They’re more academic. They seem to be different from the way they deal with him - it is quite a bit different. Yeah.</p>
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Parents, such as A_16 above and A_12 appreciated doctors who respected and valued them and acknowledged their beliefs and judgements. For example, the parent of A_12 said that she appreciated that the hospital doctors trusted her judgement, and the parent of A_16 felt more valued by the respiratory clinic doctor because he was willing to listen and discuss the parents’ views, taking an ‘academic’ approach.

6.10.1. Summary of atypical episodes – knowledge and beliefs

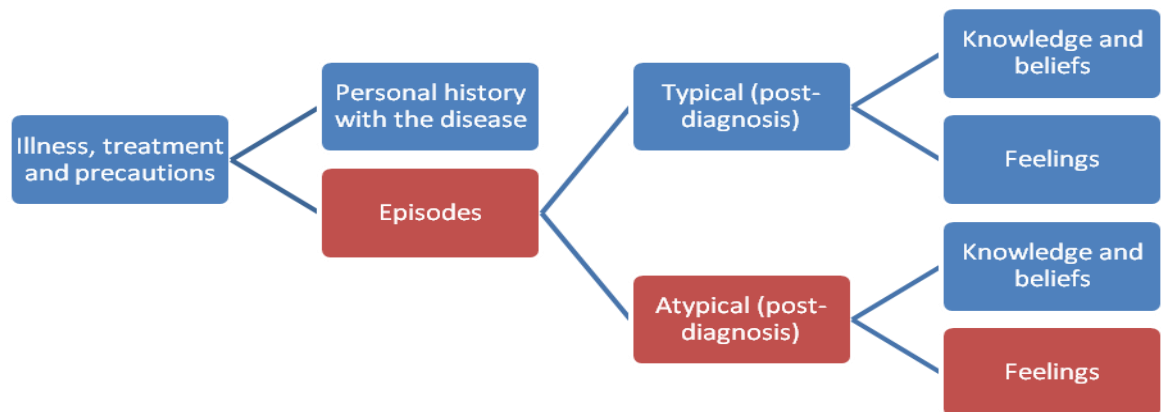
Most parents described atypical episodes, the majority of which related to an acute attack involving a hospital admission. Other less commonly-reported episodes included medication administration issues, encounters with doctors during health visits for asthma or eczema, and in one case, a hospital admission for febrile convulsions.

In the context of describing acute asthma attacks, the majority of parents demonstrated knowledge and beliefs about their child’s symptoms, treatment and / or causes of the episode. Frequently, there were time-linked changes in the kinds of knowledge and belief expressed. For example, parents tended to describe whether they initially did or didn’t recognise the symptoms of an impending attack, then referred to causes, then how the experience changed their knowledge, beliefs and related behaviour. Thus, it seems that such atypical episodes

were particularly challenging for parents, as they did not follow the usual pattern of previous asthma attacks. This may have implications for parent education, as having an awareness of unusual symptoms (or what is an unacceptable level of respiratory difficulty) might have enabled such stressful experiences to be avoided.

The second area of knowledge and beliefs expressed was about doctors, either during accounts of episodes that were acute asthma attacks or during visits to the doctor, hospital or respiratory clinic. Parents evidently believed that good doctors were very knowledgeable about asthma care, listened to and respected parents' views and competence, and responded appropriately in emergency situations. Where parents believed that such attributes or behaviours were less evident, they felt more worry and frustration.

6.11 ILLNESS, TREATMENT AND PRECAUTIONS: EPISODES – ATYPICAL (POST-DIAGNOSIS) – FEELINGS – ASTHMA GROUP



The number and nature of atypical episodes

Ten parents expressed their feelings in connection with atypical episodes (A_1, A_3, A_6, A_7, A_8, A_9, A_11, A_12 and A_15), as indicated in Appendix 6.8. With two exceptions, which were episodes involving interactions with doctors, all of these related to occasions when the child had an acute asthma attack involving a hospital admission.

Most parents described feelings in connection with only one episode (A_1, A_3, A_6, A_7, A_11, A_15 and A_16); two parents described their feelings in relation to two episodes (A_8 and A_9) and one (A_12) with three episodes.

Atypical episodes – feelings

Four kinds of feelings were expressed by parents:

- *Worry, distress and anxious behaviours (expressed by all parents)*
- *Frustration, annoyance or anger (expressed by 4 parents)*
- *Sadness and disappointment (1 parent)*
- *Positive and neutral feelings (expressed by 6 parents)*

In a similar way to parents' knowledge and beliefs expressed in the context of descriptions of acute asthma attacks, feelings in relation to these episodes altered at different times of the episode. In particular, initial feelings tended to be dominated by extreme worry or distress, such as panic reactions, shock or feelings of lack of control. Worries in the intermediate period were mentioned occasionally, such as concerns about the potential effects of the episode on the child, friends or family; finally, parents sometimes expressed new worries afterwards, such as concern their child might die or feeling more protective towards their child.

Worry, distress and anxious behaviours

These were the most common feelings expressed by parents at the beginning of atypical asthma episodes (asthma attacks). Eight parents (A_3, A_6, A_8, A_9, A_11, A_12, A_15 and A_16) described feelings such as extreme fear, panic, loss of control or competence, and worry that symptoms would worsen and therefore lead to their child dying. Some parents described how they blocked feelings to help them cope, and one parent (A_1) appeared to have used humour at a time of heightened stress during an emergency hospital admission.

After the acute phase of the episode had passed, two parents (A_7 and A_12) expressed that they felt worried about the effect of the episode on the child, family and friends. The parent of A_12 felt a need to talk about her anxious feelings, but was concerned that her children were not exposed to her expressing these.

When the child was recovering, some parents expressed new worries and anxieties, and associated behaviours (A_3, A_6, A_12 and A_15). Parents felt more protective towards their child (A_6, A_12), recalled previous traumatic episodes, re-experienced traumatic feelings and/or had nightmares (A_12, A_15). One parent sometimes thought about her child possibly dying, but only when the child had symptoms (A_3).

An excerpt from the interview of A_12 is shown below. However, it should be appreciated that that whilst the initial feelings expressed were typical of other parents, it was less common for parents to report later the same degree of interim and later anxiety, probably because this extract related to a particularly serious, life-threatening asthma attack:

Respondent	Interview Extract
<p>A_12</p> <p>Anxiety or worry expressed at different points in the episode.</p>	<p><i>At the start of the episode:</i></p> <p><i>The parent compares the approach of the hospital staff during the episode being described with a more recent experience of a hospital admission:</i></p> <p>M: But the last time when he was poorly, my GP just took us straight into the treatment room, started nebulising [child's name] and said, 'I'm going to ring an ambulance'. And that, I felt...I found that hard, because I sensed that he was worried. I sort of sensed he was not quite panicking, but he...</p> <p>I: The doctor was?</p> <p>M: The doctor, yeah. I just sensed the doctor wanted us in hospital, off his premises. You know, rather than sort of giving [child's name] at least one dose of nebuliser, seeing how he's doing, saying, 'It's OK Mom, we've been here before' and then ring in. It was, literally, he was just getting the nurse to give the nebuliser and he was ringing the ambulance. And actually I thought, 'You're making me nervous now. You're making me nervous now. We've been here before and I've done this before, but your worry is making me worry'.</p> <p>At least at the hospital, you know, they control their concern. You can feel it by the way they talk to each other. Certainly, the night that [child's name] went 'off', I knew, because otherwise there wouldn't have been four of them in intensive care all doing their bit. But they're very careful....But they still give me confidence, you know? There's not this, 'Right, let's ring the ambulance. Let's get you off the premises. Let's....' This sort of thing.</p> <p><i>During the episode</i></p> <p>M: One of the registrars in intensive care said, 'If you can stomach what's going on, can you keep talking to him. He's obviously</p>

responding to your voice, and he's staying relaxed because you're there. And I thought, 'God, can I do this?' And I was blocking out what was going on, blocking out them talking to each other, blocking out what they were doing to him, blocking out all the machines and just talking to [child's name], you know to sort of keep him calm.

And one friend of mine did come into intensive care because when I'd rung [husband's name] to say, 'When you come up today, we're not on the ward, we're in intensive care', he came up with [sibling's name] and it's very hard to see that; you know, your brother on a life support machine. So, there was not a lot I could actually say.

There was a lot I wanted to say, but I couldn't say it in front of [sibling's name]. There was no way I could have said that. So [husband's and sibling's names] went home and I could feel it. I was all in here (presses on stomach); I just knew I had to talk it out. I had to get it out, however... 'cause I had been so frightened and it had been such...like a black hole, and it had been so horrific that night. I knew if I talked it through, I would be better, you see?

So I rang a friend and said, 'I'm asking a really, really hard favour of you now. I'm asking you to come up but I just need you to listen. I'm not going to cry. I don't want you to say anything. I just need to talk it out.... They sat and they listened....And I think it's hard in society today to ask for help, or just ask somebody to listen, you know? Because we're all meant to be superwomen aren't we, you know we're in jobs and homes and we're not meant to be weak.

....[Husband's name] had immense respect for what I'd done for two weeks, but it was the hardest thing I ever did, coming away from the hospital with [child's name] still in there; it was so hard. You know, and I started to cry on the way home, and [sibling's name] said, 'It's OK Mummy. It's the best thing. He'll be alright'.

Parent reflects on the experience following the episode:

M:That [emergency hospital admission at Christmas] COMPLETELY changed ALL of our coping, perception, understanding of asthma onto an ENTIRELY different level. And as a person, I am not an anxious person. I rarely, there aren't many things in life that have ever frightened me. I've never really been a worrier, about even serious health...

But after [child's name] had been in intensive care, I now know what it feels like to be anxious, and I'm actually frightened of his asthma. And I know that's a natural response to what happened at Christmas, and I know time will probably help with some of the anxious feelings and help with some of the fear. However, having SEEN what can happen, I always knew that was part of the picture of severe asthma, but having seen it, and seen how close and how quickly they can come to dying, I feel I will always live in fear of him having an attack, until he's well out of his teens.

But yeah, so I suppose it's mainly I'm frightened. I'm not illogically frightened of it. I suppose, (doctor's name)'s word is 'respect', she

	uses the word respect for the symptoms. But there are times when I'm frightened he's going to die. You know, I'm frightened one day I will not be here, or we get him to hospital too late, or it won't be the right medical team on duty, or we'll be somewhere else in another hospital, or they won't take us seriously. You know, I know a lot of those things are illogical, or a natural reaction to Christmas, but it's, they're still not very nice sort of feelings.
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Some parents also discussed what they felt had influenced their anxious feelings (A_6, A_7 and A_12). These included being a health care professional (making the parent more aware of what could go wrong, so fearing the worst), having other worries at the same time as the episode (such as work or family concerns), feeling tired due to sleep-deprived nights in hospital and feeling social pressure to cope.

Frustration, annoyance or anger

Four parents reported that after the initial events of the episode, they experienced feelings of frustration, annoyance or anger. Some felt cross with themselves, blamed themselves or felt guilty (A_3, A_9 and A_12), either about not having responded quickly when their child developed acute symptoms or not being sufficiently supportive of other family members. Three parents (A_9, A_12 and A_16) felt frustrated or annoyed at GPs' responses, as they felt their actions were not as competent as they should have been (as at the start of the above excerpt of A_9 and A_12 below).

Sadness and disappointment

One parent also felt disappointed, wishing she had known more about recognising and responding to her child's acute symptoms (A_9):

Respondent	Interview Extract
<p>A_9</p> <p>Feeling disappointed</p>	<p>M: But I do think if someone had sat me down earlier, and talked me through things, and explained a bit better, how well steroids could control asthma, how the risks are really not that great, and the risks of not taking asthma, the right asthma drugs are greater, you know I think he wouldn't have ended up in hospital when he did. We wouldn't have put him through that big risk.</p> <p>I: So it sounds a bit like you felt partly you were to blame...</p> <p>M: Yes, I did. I felt guilty. I did feel guilty.</p> <p>I: But on the other hand, you recognised that somebody else could have done something earlier as well.</p>

	<p>M: Well, they must have seen it before. I mean, you know, for me it was the first time I'd had a child with asthma. For them, they were doctors, seeing children being admitted, seeing children coming to them regularly for long term asthma care, and I felt they should have explained things more to me.</p>
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Positive and neutral feelings

Parents commonly expressed positive and neutral feelings as well as those such as the ones detailed above. Of the six parents who expressed such feelings (A_3, A_9, A_11, A_12, A_15 and A_16), three felt secure due to the trust they had in the competence of hospital medical and nursing staff (A_9, A_11 and A_12). This was illustrated in the interview excerpt of A_12 earlier in this section. Others felt it had been useful to keep positive, and others positively reconstructed the experience afterwards (A_3, A_12 and A_15). For example, they said that they recognised that other children were worse off, that their own child could have died but thankfully didn't, and so forth. Three said they thanked God that their child had survived and/or that the situation had been controlled (A_3, A_11 and A_16). It is interesting to note that these kinds of feelings were related in the post-episode context; parents seemed to be trying to put negative experiences in a positive light, possibly assisting their adjustment to this experience.

6.11.1. Summary of atypical episodes – feelings

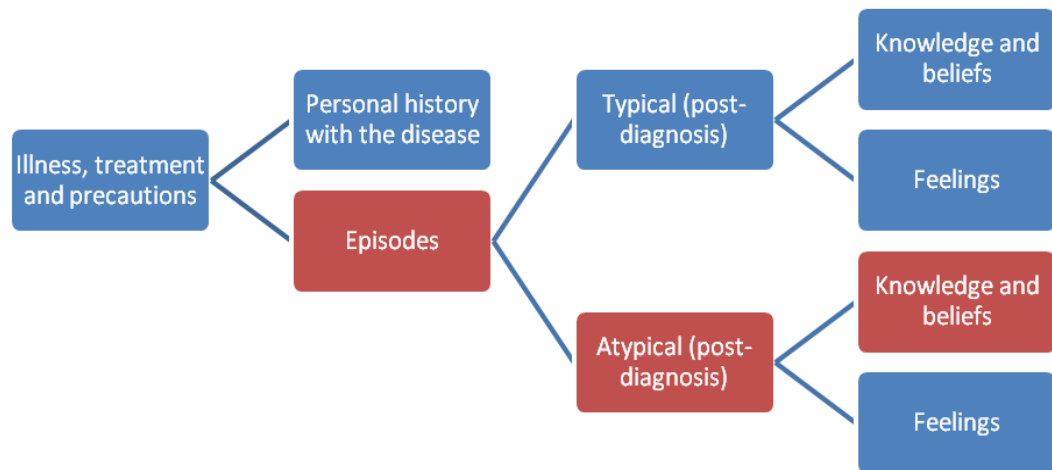
The most common feelings expressed in relation to these atypical episodes were those of worry, distress or anxiety. Unsurprisingly, these feelings dominated at the start of these unexpected and alarming episodes, and included feelings of panic and acute anxiety for the safety and survival of their child. Some parents described how later in the episode, they felt anxious about the mental wellbeing of other family members or friends, or of leaving the sick child alone in hospital. A small number of parents expressed how they continued to feel anxious after hospitalisation, for example worrying about what could happen in the future.

A few parents reflected on how they blamed or were disappointed in themselves, or blamed GPs either for the episode happening in the first place, or the handling of the events during the episode. However, many parents expressed positive and neutral feelings as well, mostly in the context of positively reconstructing the negative experience after the event.

Parents often mentioned things that they felt had exacerbated their anxiety, including work, 'societal' or family pressures, tiredness and personal knowledge of potential negative

consequences of acute asthma attacks. Health care professionals may be able to reduce some of these extraneous stressors through assessing the parents' psychological needs at different time points in such episodes, and carrying out practical measures to reduce the impact of these stressors. Perhaps health professionals also need to be more conscious of their own anxiety and anxious behaviours, which can lead to social referencing, i.e. that parents can sense the professional's anxiety, which can trigger or exacerbate a parent's anxiety.

6.12 ILLNESS, TREATMENT AND PRECAUTIONS: EPISODES – ATYPICAL (POST-DIAGNOSIS) – KNOWLEDGE AND BELIEFS – DIABETES GROUP



As explained in Section 6.1.1, this sub-theme relates to parents' knowledge and beliefs in relation to atypical health episodes; these were those that either occurred infrequently, where the symptoms of hypo or hyperglycaemia that were shown by the child were not anticipated based on prior experience and / or where the context of the experience was different from usual.

The number and nature of atypical episodes

Twelve parents or couples described knowledge and beliefs in relation to episodes that were categorised as atypical (D_1, D_2, D_3, D_4, D_5, D_6, D_8, D_9, D_10, D_11, D_12 and D_15), as indicated in Appendix 6.9. Parents described between one and four atypical

episodes. Whilst the majority of these were unique (i.e. an episode of this type happened only once), four parents described one composite episode (i.e. where two similar but atypical episodes were described together). For example, the parent of D_1 described how her child had two hospital admissions within a very short space of time where the child's blood sugars had been low, and the parent hadn't been able to bring them up. Other than these times, her son had not been admitted to hospital for his diabetes since his diagnosis.

The atypical episodes related to hypo or hyperglycaemia symptoms, although in one case (D_11), the parent was unsure whether the child's unconsciousness was due to a fall that caused a head injury, or hypoglycaemia that led to a fall.

As was the case in the asthma group, parents described their knowledge and beliefs in somewhat more detail than they did in typical episodes. Within their descriptions, parents expressed knowledge and beliefs about the following two areas:

- *Symptoms, treatment and / or causes in relation to episode (expressed by all parents)*
- *Knowledge and beliefs about doctors, the child or other people (expressed by 5 parents)*

Symptoms, treatment and causes in relation to episode (expressed by all parents)

Nearly all of the parents demonstrated knowledge and beliefs about their child's symptoms, drugs and treatment. Three of these parents described their knowledge and beliefs in the context of justifying their actions during an episode.

The time-linked nature of the parents' descriptions that was noted in the asthma group was also observed in the diabetes group. Some parents described how, at the start of the attack, they recognised the early onset symptoms or behaviours that enabled them to take appropriate action – e.g. admitting to hospital, not bringing the child home from school, giving the child food (D_1, D_6, D_8, D_15), as shown in the following extract:

Respondent	Interview Extract
<p>D_6</p> <p>Parent anticipates, recognises and responds to symptoms – no blame</p>	<p>M: We went to a party, this weekend in London, and we were camping in these friend's garden. And I went up - I had just had an inkling that she'd - I don't know I just thought, 'I bet she's woken up somehow'. And I went back to the tent, it was about half past one, and she was sitting up in bed, which she wouldn't normally do. And I thought, 'Oh she must be low'. Anyway, so she came into the house and she ate masses, and for ages she had a very glazed look about her.</p> <p>F: Yes.</p> <p>M: Anyway, she was fine.</p>

Other parents did not recognise the onset of episodes because the symptoms were unusual or else they had not been anticipated because of an apparent lack of connection between the symptoms and previous treatment behaviours, and / or parents believed they had not been alert to potential problems (D_4, D_5, D_9, D_10, D_11 and D_12). The example of D_5 later in this section illustrates the parents providing this latter reason.

A few parents (D_5, D_6 and D_15) described how their 'intuition' or knowing their child helped them to identify the onset of the episode (as shown in the excerpt of D_6 above), the best way of responding to the symptoms and / or the reason for the episode. These episodes were generally well managed by the parents.

However, a number of parents were less able to avoid or identify the significance of early signs and symptoms of an attack and respond appropriately (D_4, D_5, D_10, D_12). These episodes tended to escalate to the child having more severe symptoms. At least in part, these parents later blamed themselves or believed the episode was due to their own error, limited competence or inadequate knowledge (as shown in D_5 below). The exception was D_9, where although the parent hadn't predicted the episode, she believed that it was due to a child-specific factor (entering puberty).

The following extract shows how sometimes intermediate or later knowledge or beliefs included believing that the episode was caused by both themselves and the child (also expressed by D_4).

Respondent	Interview Extract
<p>D_5</p> <p>Unexpected symptoms, parents blame selves (not being careful enough on active day) and unusual child behaviour (extra exercise)</p>	<p>M: He has had fits before, but we've managed to bring him 'round ourself, haven't we? But this one was quite a....</p> <p>F: Well it was a low low. It was a one-point something, wasn't it? We normally catch them about 3, don't we?</p> <p>M: Actually point 9 I think we've had.</p> <p>I: (Looking at father) And were you here at the time?</p> <p>F: Oh yeah, yeah. The uncanny thing was, out of all the hypos, we knew this one needed an ambulance, didn't we, to be honest. It didn't take long to work out that this was a bad one. But it's normally tied into exercise and that day he'd had swimming, hadn't he? He'd had a very busy day that day.</p> <p>M: Yeah, he'd had his swimming lessons.</p> <p>F: So you could probably argue the fact that on the exercise front, he was well out of routines, as he'd had a really busy day. 'Cause [child's name's] not really one for sport or anything.</p> <p>M: He's not very active.</p> <p>F: So a busy day at school, and then swimming as well, and just took it over it.</p> <p>I: But you seem to have understood what was behind that, and that probably helped you later on to actually - I mean you were just saying about the swimming - so you don't sort of think, 'Oh, it's going to be unexpected'. To some extent, you feel maybe, maybe you can kind of anticipate it and make sure it doesn't happen.</p> <p>F: Yeah, we did..</p> <p>M: I'm sure he had PE as well as swimming.</p> <p>F: We looked back and decide that we are extra careful on busy days, aren't we?</p> <p>M: Yeah.</p>

In other cases, factors external to the parent were sometimes offered as the sole reason for the episode (D_3, D_7, D_9 and D_11). It was interesting to note that parents who more easily recognised and responded to early symptoms did not mention that they blamed themselves, the child or external factors for the episode occurring (D_1, D_6, D_8 and D_15). It is possible that in these cases, the parent's knowledge and beliefs gave them confidence in the

managing the episode, so they did not feel the need to apportion blame. Also, in some cases where the episode was very well managed, the parent might not been as inclined to reflect on the causes of the episode.

Four parents or couples (D_5, D_9, D_10 and D_15) reflected on the outcomes of the episode in terms of their own new knowledge or beliefs. All of these parents talked about how they now knew about actions that would help treatment management (as shown in D_5 above), and that this learning made it easier to predict problems, possibly changing their actual or anticipated future behaviours in relation to their child’s treatment management.

Knowledge and beliefs about doctors, the child or other people

Initial knowledge or beliefs about doctors were mentioned by only one parent (D_9) and one couple (D_12). These parents believed they knew their child’s needs at the time of the episode, but felt that the doctor disagreed, as shown in the example of D_12 below. In this episode, the parents decided to give their child something to eat and then take her to the Accident and Emergency Department without first testing her blood sugars, as they recognised she was having an unusually bad ‘hypo’. They felt they didn’t need to check the child’s blood sugars first, believing that their observations alone were enough of a basis on which to take this decision:

Respondent	Interview Extract
<p>D_12</p> <p>Parents believed doctor didn’t agree with their judgement.</p>	<p>F: I mean we’ve gone through sort of highs and lows with it [the diabetes], and as a family I think we’re all fairly confident that we know really what we’re doing. Again, going back to Tuesday when we were admitted, the question was asked, ‘Why did you treat her for a hypo, without first having done a BM?’ We didn’t need to do a BM. We knew exactly what she was doing, because we’d seen it countless times before.</p>

Such mismatches between parents’ and doctor’s judgements could contribute to some parents feeling undervalued, and doubting their own competence. It may be particularly important to consider how differing views are expressed by health care practitioners, recognising that both perspectives may be equally valid but for different reasons. The doctor’s perspective is based on the need for accurate measurement, as formal testing is important when staff don’t know how an individual child presents symptoms, and changes in the child’s condition have to be formally monitored. Furthermore, the information needs to be shared widely amongst other health care professionals. In contrast, the parents are much more familiar with the individual

responses / types and features of presenting symptoms in their own child, and they don't need to share the results; this makes testing less important in an emergency situation at home.

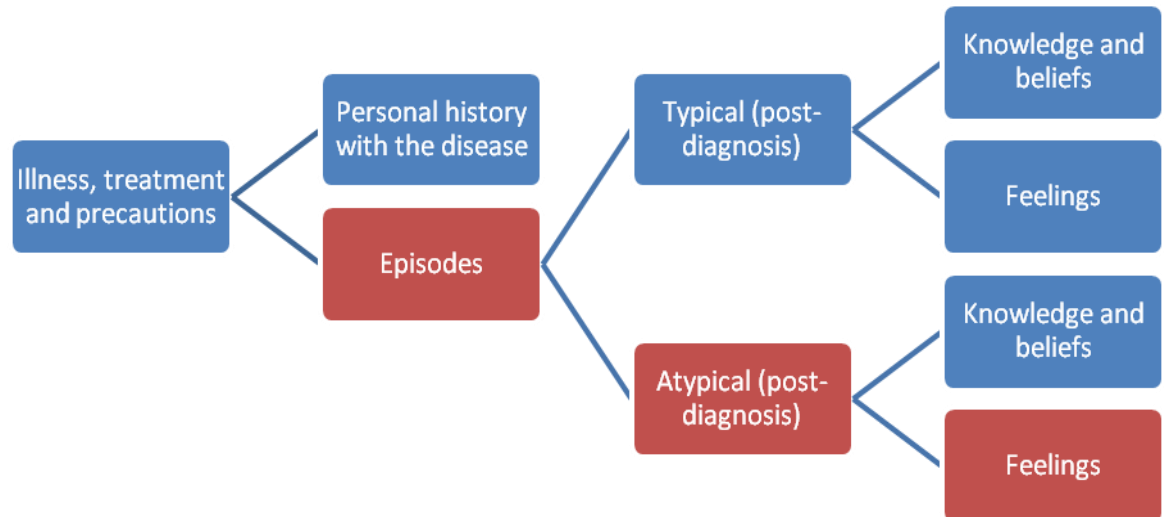
Five parents discussed their beliefs and knowledge in the context of the end of the episode. On the positive side, one parent said that the hospital information sheet and phone call to the diabetes doctor enabled her to manage the situation (D_2), reflecting favourably on the hospital staff support. Less positively, a parent blamed the doctor for not telling her that the observed symptoms could occur (D_4); another parent (D_15) believed that school staff were not well informed about how to recognise diabetes symptoms (D_15). Finally, two parents felt it was important to tell their child about their symptoms (involving behaving oddly), so they were better informed about their illness.

6.12.1. Summary of atypical episodes – knowledge and beliefs

Most parents described at least one example of an atypical episode, usually of hypoglycaemia. In most cases, these episodes were managed at home, although in a few cases the child was admitted to hospital. Most of the knowledge and beliefs expressed were time-linked (i.e. in relation to those at the start of the episode, during and then afterwards). The most typical kinds of beliefs and knowledge discussed related to whether or not parents initially recognised and responded appropriately to the child's symptoms (in their view). Connected with this was whether they discussed a cause for the episode and if so, if they blamed themselves, the child or some external factors for the occurrence of the episode. It was noted that where the outcome of the episode was more positive (e.g. managed well at home), the parent was less likely to discuss causes or apportion blame. Parents tended to blame or question their actions (at least in part) when the outcome was less favourable for the child, or the situation seemed to be less well managed. Some parents whose child had more negative outcomes (e.g. hospital admission) talked about how they learned from the experiences in order to avoid reoccurrences in the future.

A smaller number of parents expressed beliefs about others in the episode; a feature of some of these was the desire that others would learn or otherwise benefit from the outcomes of the episode.

6.13 ILLNESS, TREATMENT AND PRECAUTIONS: EPISODES – ATYPICAL (POST-DIAGNOSIS) – FEELINGS – DIABETES GROUP



The number and nature of atypical episodes

Thirteen parents expressed their feelings in connection with atypical episodes (D_1, D_2, D_3, D_4, D_5, D_6, D_7, D_8, D_9, D_10, D_11, D_12 and D_15). One parent (D_12) described two atypical episodes where the focus of the description was on another health problem, a result of which was that the child's diabetes management was affected. The first episode was where the child was admitted to hospital to have his appendix removed, but the parent felt the insulin was not managed appropriately at the hospital. In the second episode, this child had an infectious illness that was associated with difficulties in managing the diabetes. In all of the other episodes described by parents, the focus of the parent's description was on the diabetes management when the child had hypo or hyperglycaemia, although in some cases this was associated with another problem (e.g. gastrointestinal upset).

Atypical episodes – feelings

Four kinds of feelings were expressed by parents:

- *Worry, distress and anxious behaviours (expressed by 12 parents)*
- *Frustration, annoyance or anger (expressed by 7 parents)*
- *Sadness and disappointment (expressed by 5 parents)*
- *Positive and neutral feelings (expressed by 10 parents)*

Worry, distress and anxious behaviours

As was observed in the asthma group parents' descriptions of atypical episodes, the type and nature of feelings tended to be linked to particular time periods of the episode. In this group as well, feelings of extreme fear, worry, distress or lack of control were commonly reported to have been experienced at the beginning of the episode (D_1, D_3, D_4, D_5, D_6, D_9, D_10, D_12 and D_15). The fears expressed included shock or disturbance at the uncharacteristic reactions of the child, shock at having to give glucagon intramuscularly, feeling the weight of responsibility and fears that the child could die. Anxiety behaviours reported included shouting, crying and feeling physically sick to the stomach. One parent said she 'blocked reality'.

Parents sometimes expressed worries in the intermediate period about the potential effects of the episode on the child, friends or family (D_3, D_4, D_5, D_6, D_7, D_9, and D_12) or felt a 'wreck', helpless and exhausted (D_15).

The development of new worries or anxiety and associated behaviours was commonly reported post-episode (D_3, D_4, D_5, D_9, D_10, D_12 and D_15). Examples included re-living the episode (D_3, D_4), being exceptionally vigilant (D_12, D_15), over-feeding and/or testing blood glucose more than necessary at night (D_4, D_5), worrying about the child's competence and encouraging the child to take on greater responsibility (D_10, D_15). Parents also reported feeling insecure and worrying about what might have happened (D_5, D_9, D_10 and D_12) or what could happen when parents go out with friends (D_3, D_10) and worries about the competence of doctors possibly encountered in the future (D_9).

The following excerpt shows how the nature of the anxiety and responses changed over the duration and after the episode:

Respondent	Interview Extract
D_5	<p><i>Anxious feelings initially and during episode</i></p> <p>I: So how did you feel about all that really [events of the episode]?</p> <p>M: Oh gosh, I was so scared. I really thought we was going to lose him actually.</p> <p>F: Well yeah, when it happened, yeah, yeah, very scared.</p> <p>....</p> <p>M: We couldn't put it in him [the glucagon injection]...</p>

Parent's anxious feelings and behaviour during and after episode	<p>F: It took us two attempts.</p> <p>I: Because it's such a big needle really?</p> <p>F: Well, the first time was like, just like you do with his...</p> <p>M: I think I just went into shock really and I just went to the toilet and was sick.</p> <p><i>Feelings now:</i></p> <p>F: Yeah, they had to give him oxygen because he was a bit blue wasn't he, round the lips and stuff.</p> <p>M: Oh God, I won't be able to sleep tonight now, thinking about that.</p> <p>M: I worry at night, with [child's name].... We had to call the paramedics. And we had to use the injection, and he was rushed off to hospital so I do worry at night. [Father's name] always stays up now and checks his blood at midnight, 'cause I worry. So...</p> <p>M: I like to feed him up so I know he won't have another hypo at night.</p> <p>I: So that kind of worries you - a hypo, at the moment?</p> <p>F: That's the contentious issue, yeah.</p> <p>M: And that's a good 18 months I think, since he had that hypo, wasn't it? He hasn't had any...</p> <p>F: Yeah. And you're still over-feeding him. (laughs)</p> <p>M: I know. (laughs)</p>
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Frustration, annoyance or anger

Whilst a couple of parents said they did feel angry or annoyed initially at their child (D_7, D_9), most feelings of anger or annoyance were expressed at a later time (D_4, D_7, D_9, D_10, D_11, D_12 and D_15). Being cross with or blaming themselves was most frequently mentioned by parents (D_4, D_10, D_12 and D_15); others blamed or were critical of the doctors in the Accident and Emergency (A&E) or at a different hospital (D_9, D_11 and D_12) or of lay witnesses of the episode (D_15).

The following extract is from two episodes related by the same participant. In the first part of this extract, the parent blamed herself, but later felt she had learned from the experience:

Respondent	Interview Extract
<p>D_15</p> <p>Parent blames herself / is annoyed with lay witnesses of episode</p>	<p><i>Blaming self (child had a bad hypo)</i></p> <p>M: And then it was about last year, my own fault, I popped in, called in to see my friend, and on the way home, it was running a bit late and usually, you know, I carry food or something with me, but I didn't because I wasn't planning on stopping. But I thought, 'I'll pop in'. And the other kid said, 'Oh, [child's name] looks a bit funny, flopped'. And he'd gone so low, so I had to quick, get some Coke into him. And it brought him back, but that frightened me and that's why I think, 'Right, wherever I go, I take his finger prick, glucose and a snack, even if I'm not with him. So if I'm called to him, I've got it'. So it's little wake up calls that you have a jolt, saying, 'Oh, you know, there's always a potential for it to go pear-shaped', and that's what I think I learned.</p> <p><i>Annoyance at others (when other passengers were witnessing the episode on a bus where the child had a 'hypo') – different episode</i></p> <p>M: The people, you know, as they do, everyone does, says, 'God, what was that all about?' People have no idea. Absolutely no idea. They just thought, 'Oh, this boy had a tantrum'. I said, 'Oh (sighs)'. But [sibling's name], she was very good, she said, 'Are you alright Mom?' I said, 'Yeah, I'm alright. It's fine'. And I'm trying to wipe his face and he says, 'Is anyone looking, Mom?' And I said, 'No, no, it's fine. Let's just look out the window and see what we can see.' But inside, you just want to cry, 'Oh God, I can't do this'. Because it drains you.</p>

Sadness and disappointment

Parents' feelings of sadness and disappointment were expressed with regard to how outcomes of the episode influenced their own lives or feelings about their life. Two parents said how they wished life could be easier, and the child didn't have diabetes (D_6, D_11), and other parents felt disappointed about the effect on their own social life (D_3, D_10) or that they had felt obliged to leave employment (D_15).

The next extract illustrates shows how the parent's anxiety about whether her child could have an attack in her absence led to the parent being unwilling to go away with her partner. After two years, she had begun to think this would be possible, but a recent episode led her to change her mind. This disappointment was evident in the parent's comments below:

Respondent	Interview Extract
<p>D_3</p> <p>Parent is disappointed that she can't go away with partner</p>	<p>M: And she's going on an activity camp for a week this coming Wednesday, and knowing that she was in someone else's charge with a first aid unit and what have you, we had provisionally booked away a long weekend, but since the last hospital stay, I've got him [partner] to cancel it, because I actually want to be on call because if I was needed... so I still haven't got out of that yet. That's 2 years down the line, so it's a bit of a shame.</p>

Positive and neutral feelings

Initial feelings included feeling justified in the parent's own panic reactions, i.e. being self-accepting (D_10), and being practical or informing others (D_9, D_15). Telling oneself to be positive and so reassuring oneself (D_10), looking at the funny side (D_6), reconstructing events of the episode in a positive way (D_3, D_4, D_6) or feeling positive about the parent's own competence and ability to be the child's advocate (D_4, D_11, D_15). The most common positive feelings were feeling secure due to the trust in the competence of health professionals (D_1, D_2, D_3, D_4 and D_5), as shown in the following extract.

Respondent	Interview Extract
<p>D_1</p> <p>Parent feels positive about the support from health professionals.</p>	<p><i>The following episode occurred when the family was camping:</i></p> <p>M: I was on the phone in the middle of a field to [diabetic nurse's name], 'Hey, [nurses' name], he's vomiting, and his sugars are doing this, what do I do now!?' (laughs) And she tells you. And they are always - if they weren't at the end of the phone and I knew that if I had a problem and I couldn't get hold of somebody, then I would, life wouldn't be as easy. But they are brilliant.</p>

6.13.1. Summary of atypical episodes – feelings

Parents most commonly described how they were worried, distressed or anxious, particularly at the beginning of episodes. After the event, some parents continued to experience anxiety, displaying anxious behaviours (such as being exceptionally vigilant, in some cases potentially negatively affecting the child's care). Even when the parent recognised that this behaviour was not rational (e.g. over-feeding at night, or over-testing), they continued to do so long after

the episode. This would seem to suggest that parents may need particular supportive interventions in the aftermath of atypical episodes that provoked extreme anxiety or panic.

Parents who had been very anxious during an atypical episode often worried more about the future; they were concerned about what might happen, for example if they went away for the weekend and something happened to their child. This was sometimes associated with sadness, because of the effect on the parents' social life. When describing atypical episodes, parents expressed that they felt sad about their child having diabetes, wishing they didn't have it.

Where parents expressed anger, annoyance or frustration, this was usually post-episode. Sometimes blame was self-directed and sometimes directed at the Accident and Emergency (A&E) doctors or lay witnesses of the episode. Parents felt they should have been able to avoid the episode or act more appropriately; often parents said they changed their behaviour as a result. Although sometimes this was apparently valuable, at other times parents' behaviour was less appropriate (as discussed in the preceding paragraph). Where parents blamed others, it was generally the Accident and Emergency doctors, who they felt did not always understand. However, in relation to some atypical episodes, parents felt very positive towards the specialist diabetes doctors and nurses, feeling well supported by them during and after the episodes.

6.14 ILLNESS, TREATMENT AND PRECAUTIONS: KNOWLEDGE, BELIEFS AND FEELINGS IN ATYPICAL EPISODES - COMPARISON OF ASTHMA AND DIABETES GROUPS

Knowledge and beliefs

In both groups, parents gave accounts of the symptoms shown by their child during atypical acute illness episodes. Parents across the whole sample differed with regard to whether or not they recognised the significance of their child's symptoms when they were unusual in presentation or were unexpected. In the asthmatic group, parents were slightly more likely to recognise and correctly interpret their child's symptoms. Where parents recognised unusual symptoms and responded quickly to manage the situation, they were less likely to examine causes of the episode and to apportion blame (usually themselves or doctors) than those parents who did recognise the symptoms and respond appropriately, leading to a good outcome. It was noted that parents in both groups described their learning from these episodes and how their behaviour subsequently changed as a result.

Also, parents in both groups described their beliefs about health professionals (usually doctors, occasionally nurses), in both positive and negative ways. The parents of diabetic children often spoke in a positive vein about the good information and support they received at these times from specialist health care staff; however this was not always noted with non-specialist staff. More parents in the asthmatic group had negative beliefs about doctors (non-specialist); sometimes they did not trust the doctor or felt they lacked competence. On the other hand, where parents of asthmatic children felt respiratory specialists valued and respected the parents' views, they had a higher opinion of these doctors. In this sample, diabetic children would have received consistent specialist support since diagnosis, whereas this would not have been the case with most of the asthmatic children; this could account for the more negative views expressed by parents of asthmatic children.

Parents in both groups sometimes felt that they hadn't been given enough information by doctors about what could happen, which they felt might have enabled them to have avoided the episode. Both this point and the one made earlier about parents' tendency to apportion blame when there is a less satisfactory handling and outcome of an illness episode, suggests that better information for parents may be needed.

The following table summarises the kinds of knowledge or belief expressed by parents in the context of their description of these atypical episodes.

Table 6.3: Comparison of most common examples of knowledge and belief across the two groups

Kinds of knowledge and / or belief	Group where this was expressed	Always, frequently or rarely reported	Most common examples
Symptoms, treatment and/or causes in relation to episode	both groups	<p><i>Asthma group</i> – Always - all parents</p> <p><i>Diabetes group</i> – Always - all parents</p>	<ul style="list-style-type: none"> -Recognised symptoms related to onset or recovery (7) -Identified cause as external or unknown (4) or lack of parental knowledge (3) -Learning from episode improves predictions / actual or potential behaviour (4) - Did not recognise symptoms related to onset of episode (6) - Identified cause as external or unknown (5) or parent error, limited competence or knowledge (4) - Learning from episode improves predictions / actual or potential behaviour (4)

Kinds of knowledge and / or belief	Group where this was expressed	Always, frequently or rarely reported	Most common examples
Knowledge and beliefs about doctors, the child or other people	both groups	<i>Asthma group</i> - Frequently (6 parents) <i>Diabetes group</i> - Rarely (2 parents)	- Doctors don't always know what is best – may not appreciate urgency or don't agree with parent view (6) - Hospital information sheet and / or specialists' information over phone enabled successful management (2) - Parent knew child needs, unfamiliar doctor didn't (2)

Overall summary about knowledge and beliefs

All parents expressed their knowledge and beliefs about symptoms and treatment in general and also in relation to specific atypical episodes. Whilst parents in both groups often recognised symptoms related to onset of an episode, parents of diabetic children were slightly less often able to do so. Where this led to less optimal management of the episode, parents tended discuss causes and to blame themselves and/or blame doctors. Parents in both groups expressed how the experience led to personal learning that did or would influence their behaviour in future.

Parents in both groups expressed their beliefs about doctors and occasionally nurses. Whilst in both groups both positive and negative views were expressed, non-specialist doctors were more likely to be viewed negatively, especially by parents of asthmatic children. This was usually because the parent felt that the doctor did not have the same priorities as the parent or they did not have confidence in the doctor's competence. Positive views tended to relate to when doctors respected and listened to the parent, and provided good information.

Feelings

In both groups, parents reported feeling a range of emotions in association with atypical episodes, but worry, distress and anxious behaviours were the most typical. This is shown in the following table, which also shows similarities and differences:

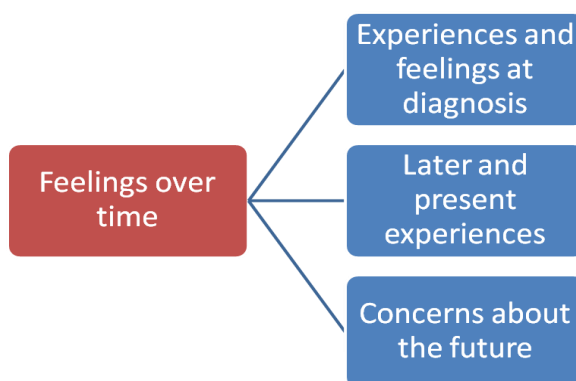
Table 6.4: Comparison of most common examples of feelings across the two groups

Kinds of feelings	Group where this was expressed	Always, frequently or rarely reported	Most common example
worry, distress and anxious behaviours	both groups	<p><i>Asthma group</i> - Frequent (9/10 parents / couples)</p> <p><i>Diabetes group</i> - Frequent (10/13 parents / couples)</p>	<p>- panic, extreme fear, shouting (initial) (4) - worry about effects on child, friends and family (intermediate) (2) - recalls previous traumatic episode; re-experiences traumatic feelings (later) (2)</p> <p>- panic, extreme fear, shouting (initial) (4) - worry about effects on child, friends and family (intermediate) (7) - worries about what might have happened or could (later) (4)</p>
frustration, annoyance or anger	both groups	<p><i>Asthma group</i> Rarely (4/10 parents / couples)</p> <p><i>Diabetes group</i> Frequently (7/13 parents / couples)</p>	<p>- cross with self / blaming self (3) or blaming doctors / feeling they're not competent (3) (sometimes combination of these)</p> <p>- cross with self / blaming self (4) or blaming or critical of doctors (3) or others (2) (sometimes combination of these)</p>
sadness and disappointment	asthma group	<p><i>Asthma group</i> Rarely (1/10 parents)</p> <p><i>Diabetes group</i> Frequently (5/13 parents / couples)</p>	<p>- wished had known more; episode might have been prevented (1)</p> <p>- disappointed at effect on own social life or employment (3)</p>
positive and neutral feelings	both groups	<p><i>Asthma group</i> Frequently (6/10 parents / couples)</p> <p><i>Diabetes group</i> Frequently (10/13 parents / couples)</p>	<p>- feeling secure due to trust in competence of hospital specialist staff (3) - being positive / positive reconstructions (3) - thanks God for child survival / situation controlled (3)</p> <p>- Feeling secure due to trust in competence of hospital specialist staff (5)</p>

Overall summary about feelings

Parents reported a range of negative emotions related to atypical episodes, most frequently relating to worry, distress and anxiety; however, they also reported positive and neutral emotions. Emotions tended to change over the period of the episode, and after the episode, often leading to new learning. Positive and neutral feelings were also reported; these most often related to how doctors or nurses helped them feel more secure, because they trusted them and felt they were competent.

6.15 FEELINGS OVER TIME: ASTHMA GROUP



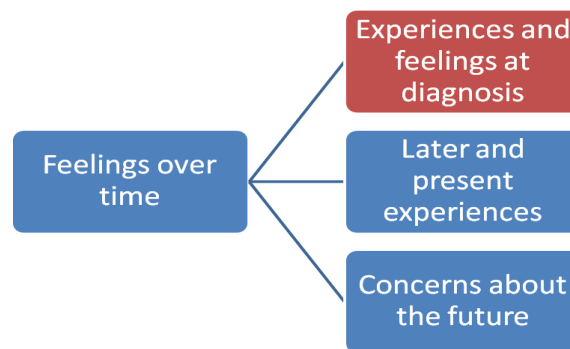
Previous sections in this chapter focused on parents' experiences during atypical episodes, but did not include an analysis of parents' descriptions of their experiences at the child's diagnosis. This period of time appeared to be highly salient for some parents, and less so for others. The reason for this seemed to relate to factors such as whether the diagnosis was expected, and the characteristics of the onset. Parents also described their present experiences and feelings and how these had changed since diagnosis. Finally, many parents talked about their thoughts, concerns and hopes about the future.

These data should offer insights relating to factors that influence the parents' experience and adjustment over time. This includes the impact of the illness course; in the case of asthma, this was not necessarily predictable, often involving changes in disease severity and ability to control the symptoms over the number of years since diagnosis.

As some of these issues were previously discussed by parents in the context of describing illness episodes, this section of the Chapter will only highlight those points that offer

additional insights. Rather than offer a detailed presentation and analysis of examples, a more discursive style will be adopted. However, detailed information about parents' descriptions may be found in Appendices 6.11, 6.13 and 6.15.

6.15.1. Feelings over time: experiences and feelings at diagnosis - Asthma group



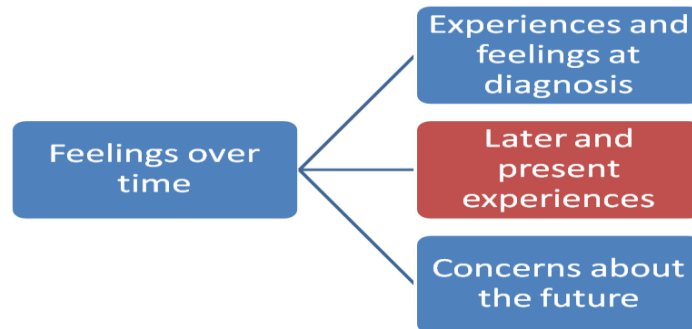
Approximately half of the parents described the child's symptoms at diagnosis as being mild (for example occasional night-time wheeze or cough); the remaining parents described more severe symptoms, including breathlessness. Some children of the latter group were diagnosed following a severe attack. Unsurprisingly, these children's parents were more likely to describe anxiety, distress or worry at the time of diagnosis. (See the green highlighted columns within the table in Appendix 6.11). In contrast, Appendix 6.11 also shows that parents of children with a less severe onset reported feeling more hopeful, not worried or able to adapt easily. Therefore, it seems that initial disease severity and characteristics of onset influence parents' adjustment early in the illness course.

Many parents talked about when the 'label' of asthma was given to the child's symptoms; sometimes this happened soon after symptoms appeared, but in other cases this did not occur for some time. A couple of parents described a sense of relief at having a diagnosis. Parents of children whose diagnosis occurred at or soon after a serious attack (indicated in pink highlighted columns within the table in Appendix 6.11) would have needed to adjust to both an immediate serious illness and the realisation of the diagnosis. This may have contributed to the anxiety, distress or worry reported particularly in this group of parents at diagnosis (as shown in Appendix 6.11, participants A_2, A_5, A_8, A_15).

A number of parents discussed their evaluation of the experiences at the time, such as feeling bewildered or asking 'why?'. This didn't seem to be related to when and how the diagnosis occurred. A few parents mentioned that the diagnosis was unexpected and one that it was

partly expected. Three of the four parents who had felt bewildered or were asking ‘why?’ engaged in problem-solving efforts shortly after diagnosis (A_5, A_10, A_15), which may have helped their early adjustment.

6.15.2. Feelings over time: Later and present experiences - Asthma group



The experience of the child’s illness was quite variable in some cases, with different turning points in their child’s asthma severity over the illness history. Some children initially had mild symptoms which worsened, then occasionally improved. Other children had severe symptoms that became less so, then sometimes worsened.

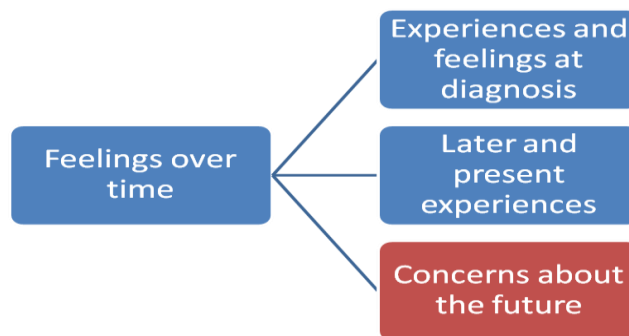
However, regardless of the illness course, many parents expressed worries about issues concerning the illness or its effect on the child or family. Most parents said that they felt anxious at times about their child’s health or illness management. For some parents, these anxious feelings were quite mild and occasional (e.g. A_3, A_8), whereas other parents were preoccupied with and observing for symptoms much of the time (A_7, A_12 and A_16). This degree of anxiety is perhaps not surprising in these three parents who had children with severe asthma. Other feelings expressed by some parents included guilt about possibly being too complacent, sadness for the child or that they hadn’t grown out of asthma, and disappointment, anger and frustration directed at others. All of these feelings were also reported in the context of typical and atypical episodes described in earlier sections.

Positive and neutral feelings were also expressed by parents, such as feeling they were adjusting to the demands of the illness, were more accepting or were finding the disease easier to manage (A_2, A_4, A_8, A_15, A_16). Again, these were parents of more severely affected children whose asthma had either always been severe or had changed to becoming more severe. With the exception of A_16, these were not the parents (referred to in the previous paragraph) who expressed significant anxiety. It is unclear why this might be the case, although length of time since diagnosis might be a factor. The children referred to in the

previous paragraph had been diagnosed between 2½ and 6 years, and with one exception, those referred to in this paragraph were diagnosed between 10 and 13 years ago.

Finally, if parents had seen recent improvements in their child’s health, they felt happier, relieved, or more relaxed (A_3, A_6). These were both parents of children whose asthma had originally been mild, had then worsened but recently improved. Therefore, both length of time since diagnosis and illness course (showing improvements or not) may contribute to adjustment in the years following diagnosis.

6.15.3. Feelings over time: Concerns and hopes for the future - Asthma group



About half of the parents expressed their hopes for their child’s future, the most common being that the child would ‘grow out of asthma’, or at least that the illness or life impact would lessen. Their concerns in the short-term focused around issues such as whether the child’s school would cope with the asthma safely and knowledgeably. Longer term concerns related mainly to worries about drug side effects, that asthma would get worse in future, or would hinder their future life or independence.

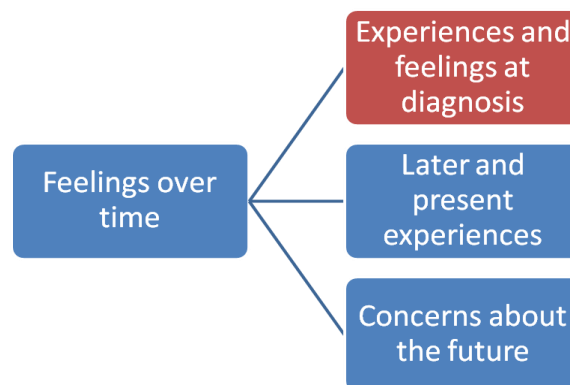
6.15.4. Summary of feelings over time – Asthma group

This analysis has suggested that parents’ adjustment varies, and may be influenced by a range of factors. Differences in how the diagnosis arose seemed to be influential, with those parents whose children had more severe initial symptoms describing a high degree of anxiety, distress and / or worry at that time. Parents of more mildly affected children were more hopeful, less worried and reported that they had adapted without much difficulty.

Later and present feelings expressed were both negative and positive, as was the case in the data relating to episodes described earlier in this Chapter. Parents varied in the degree of anxiety they expressed, with some reporting a high degree of preoccupation with observing and monitoring behaviour, and others reporting more mild and occasional anxiety in relation to their child's illness or its management. These latter parents tended to report that they were adjusting or managing better than those who had expressed more significant anxiety. One reason for differences could be length of time since diagnosis, since the children of the less anxious parents had usually been diagnosed for longer. Another reason for expressing optimistic or positive feelings was the illness course; a couple of parents whose children's asthma had shown a recent improvement were more hopeful about their child's health.

6.16 FEELINGS OVER TIME: DIABETES GROUP

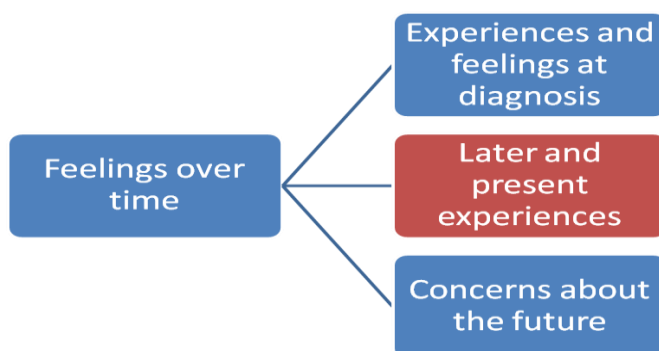
6.16.1. Feelings over time: experiences and feelings at diagnosis -- Diabetes group



Most parents did not suspect their child had diabetes prior to the diagnosis of their child's diabetes, or else they only suspected this at a late stage. In some cases, the child had been ill for some time before a diagnosis was made. In five cases, the GP initially misdiagnosed or never diagnosed the symptoms as being due to diabetes. Prior to diagnosis, some parents did not think there was anything seriously wrong with their child, or thought the cause of the child's symptoms was psychological, thus leading to a delay in going to the doctor. In a number of cases where there was a delay in diagnosis, parents felt guilty that they had not acted differently, and/or felt angry that the diagnosis had been missed. This was often accentuated by the fact that the child was usually somewhat more ill by the time treatment commenced. Many parents described being shocked, with some saying they tried to deny the truth. Parents also described feelings of sadness or loss, frequently feeling distressed and bursting into tears.

When parents described their evaluation of the situation, most said they felt bewildered and ignorant about diabetes and its management. They worried about the impact on the child and / or other family members, and about making mistakes. Only one parent felt a sense of relief. A couple of parents tried to find a reason for why it happened (e.g. genetics). It was evident in the interviews that the experience had usually been very distressing, and still caused them distress when thinking about it; six of the parents cried during the interview when describing their experiences at this time, with others describing their experience in vivid detail. Thus, this period of diagnosis was evidently a highly emotional time for most parents.

6.16.2. Feelings over time: Later and present experiences - Diabetes group



At the time of the interview, most parents (13 out of 16) reported that they had adjusted life to the demands of the illness, had incorporated the diabetes management into their lives and felt more in control. The children of these parents had been diagnosed for between 2 and 12 years. The three parents who did not feel this way, reporting that they were starting to learn to cope with it, or not managing to do so, were parents of a child diagnosed one year previously (D_13), a parent of a teenager who the parent said had never accepted diabetes (D_7), who said she felt things had not gotten better since her child's diagnosis six years previously, and she herself felt just as bad. The other respondent who did not report positive adjustment was D_2, whose interview was atypical because it had primarily focussed on the respondents' views as a support group leader. Thus, it seems that most parents felt they had adjusted quite well following their original significant difficulties, if their child had been diagnosed for at least two years.

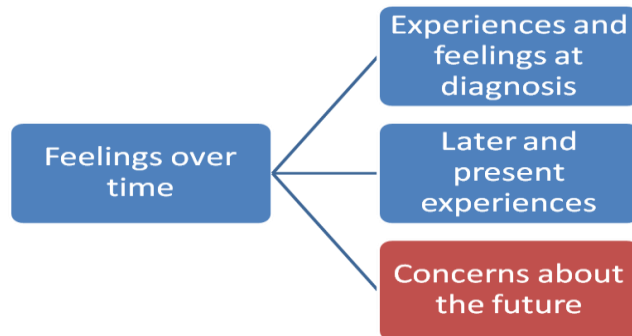
Negative feelings were expressed by parents, for example that 'it takes over your life' (D_12, D_13, D_15). Two parents whose child had been diagnosed for just two years (D_5, D_8) expressed concern that they still got the diabetes management wrong sometimes, and two parents whose child had been diagnosed for one or two years felt that they still lacked knowledge (D_5, D_13). Thus, it seems that the first couple of years following diagnosis may be particularly challenging for parents, as they gradually gain the necessary understanding and skills to manage their child's care effectively, without impacting disproportionately on their lives.

Anxiety and worry were expressed by most parents, although usually this was mild and infrequent. However, five parents reported significant anxiety at times, for example, 'being consumed with worry' when control was bad (D_15). Parents' worries tended to focus on the child not being reliable (or thoughts that they might not be reliable) in managing their treatment, or difficulties in getting the child's blood sugars right, which didn't always happen despite their best efforts.

Some parents felt sadness at times, for example about their child not accepting the diabetes, not having good control, the impact on the child's life or relationship issues. A few parents described disagreements with their partner / spouse over management, which was stressful for them. Frustration was also expressed, particularly about others' ignorance concerning diabetes.

Some neutral or mixed feelings expressed by parents included that they were continuing to learn all the time, doing their best within the limits of their knowledge. A few parents compared their own situation to that of others who were worse off, which made them feel better when they felt sad. A number of parents expressed the wish that they could change places with their child. Others discussed how factors other than diabetes affected how they felt about it, such as the challenge of parenting an adolescent with diabetes, or family difficulties.

6.16.3. Feelings over time: Concerns and hopes for the future – Diabetes group



A number of parents expressed their hopes for the child's future, for example that they would be confident in life and able to do normal things, whilst managing risk. A couple of parents expressed hope for a cure for diabetes.

The most commonly expressed concerns about the future related to possible long term complications of diabetes, or whether as their child entered teenage years or left home, they would maintain diabetes control. Some worried that diabetes would hinder their child's lives. A couple of parents worried about a sibling getting diabetes. However, overall the focus of concern for most parents was the need to avoid poor control or correct poor control. Those whose child had existing poor control were unsurprisingly particularly concerned. Thus, the child's poor control is likely to influence parents' adjustment adversely.

6.16.4. Summary of feelings over time – Diabetes group

It was apparent that for most parents, the time of diagnosis was very difficult at an emotional level, but also it was challenging to understand and get to grips with managing the diabetes. By two years post-diagnosis, most parents felt they had adapted, fitting diabetes into their lives. However, many continued to feel anxious about having good diabetes control, and their future worries concentrated in the same area (i.e. concerns about future complications or their child having control when away from the parent, such as at university). Therefore, whilst parents felt they had adapted, it is likely that worry about their child's current and future control was an evident source of stress.

6.17 FEELINGS OVER TIME: COMPARISON OF ASTHMA AND DIABETES GROUPS

Experiences and feelings at diagnosis

In general, the time of diagnosis was a more distressing experience for parents of children with diabetes than those whose child was diagnosed with asthma. The parents of diabetic children had to cope with what was usually a shock of the diagnosis, and sometimes observing the deteriorating health of the child preceding this, without knowing the reason. Also, they needed to learn quickly about the disease and how to manage it well; many felt they lacked understanding and ability to manage the diabetes. Comments that diabetes ‘takes over one’s life’, and that they were worried about making mistakes were fairly typical.

Whilst for some parents of children with asthma the onset was sudden and severe, in all cases, they had observed respiratory symptoms and sometimes said they suspected that the child had asthma. Thus, in these cases, they would have been able to prepare themselves emotionally for the diagnosis. This is supported by the finding that, unlike in the diabetes group, parents did not describe feeling shocked and, unlike a number of parents in the diabetes group, did not often report feelings of sadness and loss or exhibit distress when describing the experience. In fact, a couple of parents described the diagnosis as a relief, now having a reason for the symptoms. Nevertheless, the group of parents whose onset of asthma symptoms was sudden and severe reported more initial distress; possibly this was due to their having to deal with both the diagnosis and an acutely ill child.

Thus, it appeared that in general, the parents of children with diabetes found the time of diagnosis more emotionally and intellectually demanding; it was more shocking and harder to adjust to. However, those parents of asthmatic children who had a severe and abrupt onset of symptoms preceding the diagnosis found the time of diagnosis more distressing than others in this group. Thus, the severity of the symptoms at diagnosis, the degree of unexpectedness of the diagnosis and demands of treatment seemed to be important for parents’ adjustment at this early stage.

Later and present experiences

Most parents in both groups felt they had adjusted to the diagnosis at the time of the interview. However, several parents of more severely affected asthmatic children described how they often felt very anxious, being preoccupied with monitoring the child's symptoms; these parents did not report a belief that they were adjusting to the child's illness. It was noted that the children of these parents had been diagnosed for a shorter length of time than other asthmatic children in this sample. A few parents in the diabetes group did not report they had adjusted to their child's illness; one child had been diagnosed within the last year, and the teenage child of one parent had not yet accepted his diabetes. Therefore in both groups, time since diagnosis and possibly child adjustment seemed to be a possible reason for less optimal adjustment.

Parents of diabetic children more often reported feeling worried, particularly about whether the child had good control. Some had disagreements with their spouses about the child's management, and it was common to report frustration with others' ignorance. Some parents of asthmatic children reported feeling more relaxed if their child's condition had improved. Therefore, there was more variation in the experiences and feelings of the parents of asthmatic children, linked to variations in the asthma severity.

Concerns and hopes for the future

The parents of asthmatic children tended to be more optimistic about the future, often expressing a hope that the child would 'grow out' of the asthma, or at least that the effects and life impact would lessen. In contrast, parents of diabetic children did not often express optimism about any improvement in their child's condition, although the hope for a cure was sometimes mentioned. However in both groups, some parents expressed significant worries; in the asthma group these tended to be about the long-term side effects of medication, whereas in the diabetes group, these often related to the long-term complications of poor blood glucose control. Whilst it is difficult to generalise, the parents of diabetic children appeared to experience more anxiety and less hope about the future, which could influence their adjustment more significantly.

6.18 GENERAL DISCUSSION AND IMPLICATIONS FOR THEORETICAL MODEL

This discussion will focus primarily on an analysis of findings relating to Objective 3, which is to ‘Examine the parents’ experience of the effects of the child’s illness and its management over time, as the years since diagnosis increase and as their child develops and matures.’ This involves an examination of the parents’ experience of the child’s illness and its management over the years since diagnosis. This time period includes consideration of typical and atypical illness events or episodes that punctuate the parent’s and child’s overall illness management experience.

Further, it is anticipated that insights beyond those gained in Chapter 5 will be discussed. Although Objective 2 similarly emphasises illness experience, this is not in the context of particular illness episodes. As a reminder, Objective 2 was to ‘Examine similarities and differences in illness and treatment features and the illness management experiences of child and parent; consider the significance of these for the child’s and parent’s adjustment. As in previous Chapters, Objectives 5-8 have an important, although implicit influence on this discussion.

The data relating to the themes and sub-themes considered in this Chapter offer useful insights into answers to a number of questions related to the parents’ experience of the illness over time. These include, ‘How do features of the child’s illness and illness episodes affect parent adjustment, and are these different for the two illness groups?’, ‘To what extent do the health professionals, teachers and others who may be involved in medical care have a shared understanding of the parents’ experience?’, ‘How and why do parents sometimes respond differently in similar circumstances and illness episodes, and how do these responses influence or reflect their adjustment?’ and ‘Is the degree of predictability of illness episodes and hospitalisations, frequency of illness episodes, and severity of attacks important for parents’ adjustment?’

As in previous chapters, schematic diagrams, which are displayed in Appendices 6.17-6.25 on pages 137-145, will be used to support the discussion. Some reference may be made to findings from previous chapters, where relevant. The reader is again referred to Chapter 3, Section 3.4.2.4, for the key for symbols in these diagrams. The discussion will conclude with a summary of the central elements proposed for inclusion in the theoretical model.

Personal history of the Illness

The data relating to the theme ‘personal history of the illness’ is a useful one to initially consider when analysing the experience of parents over time. Personal or family history helps to explain the meaning of the diagnosis for parents as well as their reactions to the diagnosis and their initial adjustment. The data analysis showed that although there were some exceptions, most parents in the asthma group reported a family history of the illness, which influenced their responses at the time of diagnosis. (See Appendix 6.17, Schematic Diagram 16 on page 137). For most of these parents, the diagnosis was not a shocking experience as their family history had given them some preparation for this possibility, and initial adjustment was reported to occur relatively soon after diagnosis. Furthermore, support was often available from other family members affected with the illness. Having family members who are knowledgeable about the illness and who provide emotional and practical support are likely to help the parents’ early adjustment.

This is in contrast to the experience of parents in the diabetes group, where few parents had a family history and typically had little prior understanding or experience of this illness. Furthermore, not having relatives with illness expertise was a disadvantage, as parents often felt ill informed and confused about the illness management in the early days, which contributed to their anxiety. These were some reasons why the diagnosis was shocking, and parents felt such distress at the diagnosis. Adjustment took somewhat longer than in the asthma group, with a number of parents reporting that they started feeling more able to integrate the illness management into their lives after about 2 years. These experiences and responses are reflected in Appendix 6.18, Schematic Diagram 17 on page 138.

Where parents in both groups had a family history, some differing experiences were reported. Parents in the diabetes group who had relatives with the illness talked about their negative images and beliefs relating to the illness; these influenced parents’ initial expectations concerning the child’s diabetes. They often expressed guilt for having passed on an illness of this level of severity. In contrast, parents in the asthma group usually had positive images of relatives with good outcomes / improved health. However, this was not true in one case where there was a lot of variability of degrees of asthma severity amongst relatives. Whilst the immediate family had mild asthma, some extended family members had severe asthma. This parent had assumed that the child’s asthma would not be severe, so was shocked when this was found to be the case.

Experiences of typical and atypical episodes

When considering the question relating to the effects of illness over time, it has been informative to analyse the impact of typical and atypical illness episodes, partly because adjustment is evidently easier when episodes have a predictable pattern. For example, Diagram 18 shows that in typical episodes of both illness groups, repetitions of similar events enabled parents to predict events within the episode. Where parents' had learned from prior similar experiences, handled them well and where the episode had positive outcomes, the typical episode was not too stressful. These often led to increased parent confidence and high self-efficacy.

Atypical episodes differed in that these events were unexpected and unusual, so parents were less able to draw upon their prior knowledge and experience. This lack of anticipation meant that such episodes were often frightening for parents, and having little knowledge or understanding about causes and/or symptoms led parents to feel less able to control or respond confidently, as illustrated in Appendix 6.20, Schematic Diagram 19 on page 139.

This point is useful to consider when revisiting the question about whether the degree of predictability of illness episodes and hospitalisations, frequency of illness episodes, and severity of attacks is important for parents' adjustment. The pattern of parents' emotional responses in atypical episodes are understandably characterised by more distress than in typical episodes. Also, parents in these situations sometimes panic, leading to less effective treatment interventions. For example, some parents said that if they had they known about such possible symptoms (e.g. D_4 describing extreme child behavioural changes in hyperglycaemia), they would not have panicked and could have intervened earlier in treatment. Such very fearful atypical episodes were vividly recalled by parents, and some experienced continuing anxiety years later. This has some important lessons for health professionals with regard to providing information for parents about the range of symptoms they might observe, and potential precursors of these.

Severity of the child's symptoms in atypical episodes is likely to also be relevant in these situations, adding to parents' anxiety about the possible consequences for the child. With regard to the issue of frequency of illness episodes, this seems to be less important than the unexpected nature and severity of episodes, i.e. if episodes are mild, high in frequency and unthreatening, they do not seem to be highly emotionally demanding for parents.

However, typical episodes can be distressing for parents, particularly when they feel less supported by health professionals. Parents' accounts about the behaviour and/or attitudes of doctors in typical episodes suggest that these contributed to making the experience less or more stressful. One aspect of these accounts was that parents believed that doctors' priorities were sometimes different from their own, and another aspect was about whether they trusted and felt respected by doctors.

In Appendix 6.21 on page 141, Schematic Diagram 20 reflects data relating to parents' evaluations of such episodes in the context of interacting with doctors. Where parents judged that they themselves had a high degree of knowledge and expertise, they often felt frustrated or angry where doctors appeared to know less than they did, and also did not respect their expertise and judgement. Furthermore, a number of the parents who did not respect or trust the doctors' judgements (usually a GP) sometimes then ignored or did not later seek the doctor's advice, and sometimes took significant independent decisions (e.g. to discontinue a medication). This is a useful point to consider when evaluating patient or parent adherence as well as parents' support.

As mentioned earlier in this chapter, this type of experience with doctors was an unusual feature for parents of diabetic children, who generally expressed that they had excellent support from a specialist diabetes team of doctors, nurses and allied health professionals (and did not generally access support from other doctors). Where negative experiences occurred, it was normally when the child was being cared for by unfamiliar or less experienced doctors. As the episodes in this illness group typically occurred in school rather than hospital, parents were more likely to express stress related to inadequate health care support for their child from teachers, rather than from doctors.

Thus, when considering the question, 'To what extent do the health professionals, teachers and others who may be involved in medical care have a shared understanding of the parents' experience?', the above findings are important, and highlight the importance of knowledgeable and respectful care. With reference to Appendix 6.22 on page 142, it is also helpful to consider Diagram 21, where there is a key factor 'Feels supported / well advised by health professionals'; for parents of asthmatic children in particular, this was a strong feature of their experience – either in a negative or positive way.

Clearly if experiences in typical episodes were negative and hard to manage, the outcome was less positive for parent's adjustment. Factors identified from the data that contributed to whether or not parents coped well during typical episodes are shown in Schematic Diagram

21. Differences between parents in relation to their expressed emotions, coping and self-efficacy were evident, even when features of episodes were similar. This offers further insights into the question, ‘How and why do parents sometimes respond differently in similar circumstances and illness episodes, and how do these responses influence or reflect their adjustment?’ It was evident that parents felt that they had coped more effectively when they had good coping resources and a supportive environment. Additionally, previous success in managing typical episodes promoted greater self-efficacy. These factors will be important for health care professionals to recognise as parental coping strategies, and consider whether some of these may be enhanced when planning supportive interventions for parents.

Cognitive appraisal of episodes also influenced parent adjustment. In Appendices 6.23 and 6.24 on pages 143 and 144, Schematic Diagrams 22 and 23 illustrate how parents vary in how they later reflect upon, interpret the episodes, and later act on learning. As highlighted in Chapter 5, parents look for causes or reasons for occurrences in illness management experiences. Where parents were able to identify causes, these were either controllable or not, which influenced their worry about future attacks and self-efficacy. For example, not knowing a trigger for an asthma attack does not allow future prediction, but believing the cause was lack of information is resolvable through parent effort. Many parents reported changed perspectives and behaviours (particularly after atypical episodes), because of the emotional associations (e.g. worry about child death). The implications of this for parents’ emotions at particular points (e.g. anxiety, frustration, self-blame) and self-efficacy is shown in Diagram 23.

When considering the experience of parents over the illness course, Diagram 24 offers some helpful insights. The nature of the illness onset and symptoms are evidently important in early adjustment, as touched upon briefly in this discussion. This diagram shows how the features of the illness onset, illness course and potential for the illness to decline in severity or disappear differ between the two illness groups.

These illness features also help to explain differing patterns of feelings and actions reported by parents at different points in time across the two illness groups. It should be recognised however that Diagram 24 illustrates typical patterns; there were also cases where children with asthma and their parents did not adjust easily, particularly when there was a more sustained period of severity (rather than the more typical variability with seasons, environments or other factors), or where there were frequent severe episodes. For example, the child of D_14, a poorly controlled diabetic, reported the most typical episodes in this illness group, the majority of which were hospital admissions or episodes of severe hypo or

hyperglycaemia. These parents were among those who had experienced the most difficult adjustment. There were similar examples in the asthma group (e.g. A_5, A_7, A_8).

These findings also make it clear that the pattern of illness course (e.g. if characterised by typical severe episodes) can strongly influence adjustment. This point is further emphasised when considered alongside the data relating to personal history of the disease and those from Chapter 5 (relating to the generally more complex and burdensome treatment management in diabetes). Thus, when reconsidering the first part of the question posed earlier of ‘How do features of the child’s illness and illness episodes affect parent adjustment, and are these different for the two illness groups?’, it is possible to conclude that illness features such as heritability, timing and mode of onset, characteristics of the illness course and potential for improvement are indeed influential in parents’ adjustment.

Key insights relevant to the theoretical model

Features of the illness and illness course over time that influence parents’ adjustment

- Illnesses with high heritability and known relatives with the illness (especially where the illness is well managed) can help parents anticipate and prepare for a diagnosis.
- Relatives who have the illness, have high expertise and are supportive help parents to make better initial and subsequent adjustment.
- Where the illness has low heritability, there are no known relatives, or where the relatives’ illness was poorly managed or where the degree of severity did not match parent’s expectations of the child’s illness severity, initial adjustment was more difficult and often shocking for parents.
- Illness features including nature of onset, illness course and potential for the illness to disappear affects parent’s illness experience and adjustment. Additionally, results from Chapter 5 showed that parents tended to find that having a diagnosis when the child was very young enabled them to adapt more easily; diagnosis during later childhood and adolescence (often the case in diabetes) was more often associated with difficult initial parental adjustment.

Features of and responses to illness episodes

- Illness episodes that are typical help parents to develop knowledge and skills for applying in future similar episodes; however where episodes are severe and very frequent, cumulative stress is more likely.
- Illness episodes that are unexpected and atypical are more difficult for parents, as they are not able to draw upon prior knowledge and skills about illness management.
- Parents reflect on the causes, feelings, consequences and outcomes of episodes and assess future risks; this process influences their cognitive and emotional associations with the episode, beliefs, learning and subsequent coping and self-efficacy.
- Atypical episodes that evoke fear and lack of control are most stressful for parents, and may lead to less confident subsequent illness management, as well as subsequent chronic stress.

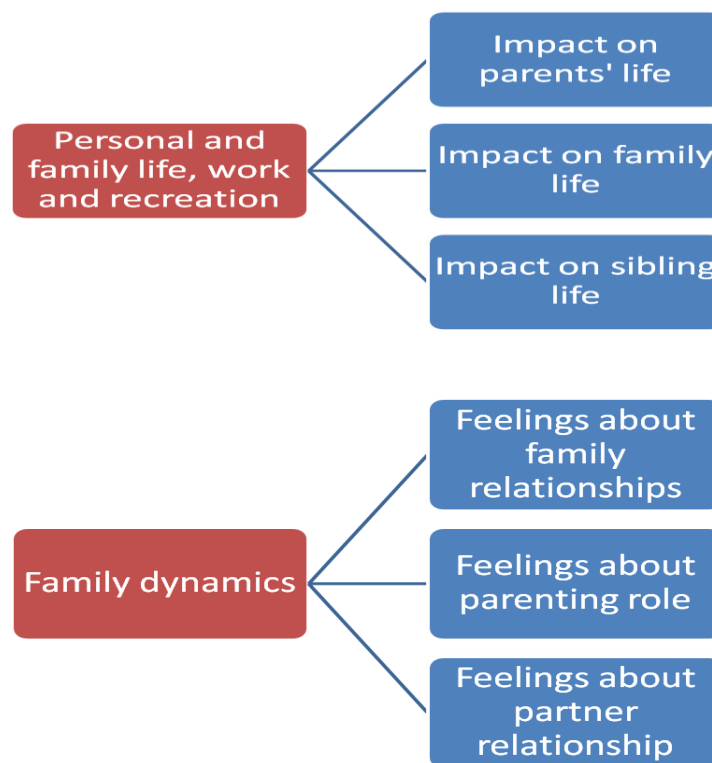
Relationships with doctors

- Parents find it easier to cope better in typical episodes when doctors have particular characteristics and behaviours that show empathy, respect and expert knowledge and skills.
- Parents are more likely to listen to and adhere to advice offered by doctors with these positive characteristics and behaviours.

CHAPTER 7: EFFECT OF THE ILLNESS ON PARENT AND FAMILY LIFE

7.1 INTRODUCTION

This Chapter will consist of the analysis of results of two themes and associated sub-themes as indicated in headings shown in the diagrams below. The description and explanation of each of these will be presented in section 7.1.1.



Structure of this Chapter

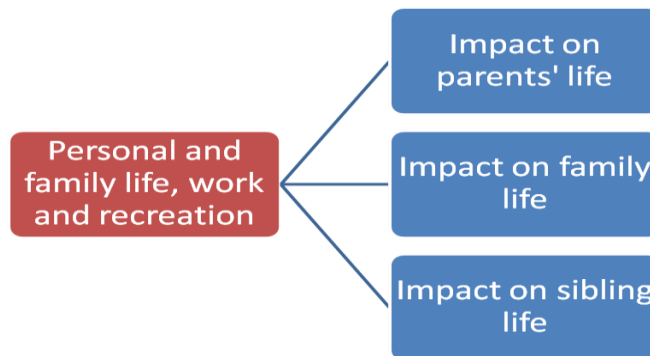
As with previous Chapters, a grounded theory methodology has been used, and will contribute to the model for parental adjustment that was partially formulated in Chapters 4, 5 and 6. However, the structure will be in a modified, abridged format; this is because much of the data coded at these themes has been touched upon previously although in a different context (such as when parents discussed how their personal lives were affected following episodes, how family members were supportive during episodes, parent responses to children's internalising and externalising behaviour, and so forth).

This different structure of reporting findings will therefore be more concise. Although the results of the asthma group and then the diabetes group will be reported, discussed and compared, the structure will contain fewer sections and sub-sections. Previous chapters presented findings of the asthma group followed by a summary, then those of the diabetes group and a summary, and then a comparison of similarities and differences, and overall summary. In this Chapter, issues common to both illness groups will be presented and discussed in a single section (using examples first from the asthma and then diabetes groups), followed by a summary. As many of the issues raised by parents in both groups in relation to this Chapter's themes were the same, this procedure will avoid repetition of these issues in separate illness group sections. In cases where any fundamental group differences are present, a further section will be included on aspects unique to each disease group. Some of the tables in Appendices 7.1-7.12 are also of a different style (containing more detail). This allows the reader to examine data further if required. The Chapter will end with a cross-group comparison, and overall summary of the sub-themes and any further additions to the theoretical model presented in previous Chapters.

7.1.1. Explanation of themes considered in this Chapter

The two themes in this chapter are inter-connected, as both relate to parent and family functioning in everyday life. Unlike other themes explored in previous chapters, the illness or treatment of the child is not a central feature. Rather, it considers the consequences of the child's illness or treatment management for parent and family life. The nature, extent and perception of these consequences varied between parents, with some apparently perceiving these as more severe than others, and with some being more able to overcome obstacles than others. Understanding the reasons for differences in such perceptions and behaviour of parents will be important when considering the significance for their adjustment. For example, differences could illustrate variations in coping strategies as well as those related to the disease, its severity and child's age.

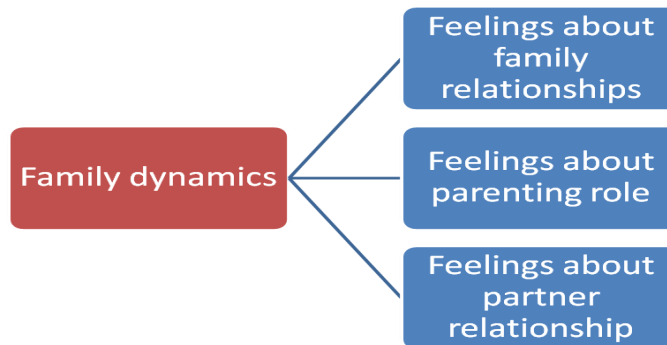
Personal and family life, work and recreation



The first major theme, '*Personal and Family Life, Work and Recreation*' refers to the practical consequences for the parent and family of having a child in the family with a chronic illness, together with the parents' perceptions of these consequences and actions about them. These practical consequences are those reported about the impact on the parent's personal life, for example in the areas of working life and with regard to recreational activities as an individual, or with friends or partner (i.e. first sub-theme) and those affecting family activities such as family outings and holidays (i.e. second sub-theme). It also includes the psychological life of parents, in particular their mental health.

'*Impact on Sibling Life*' relates to how siblings act and feel in response to having a sibling with a chronic illness. This was not categorised as a sub-theme under '*Family Dynamics*' because it does not typically describe dyadic interaction between the children. It refers to what the parent (and sometimes sibling) reported as the sibling's psychological and physical responses resulting from the child's chronic illness. Events that parents believed influenced sibling responses included giving children with and without a chronic illness different levels of attention, applying different rules about snacks (in diabetic group), having experiences where they had witnessed distressing behaviour during acute episodes, and parent expectations and demands for their helping with or supporting treatment. Siblings varied in their emotional and behavioural response to such events and expectations. This sub-theme is slightly peripheral to the topic of parent adjustment, although it is related to parenting role, which is discussed in the context of the next theme.

Family dynamics



This theme relates to parents' perceptions of and feelings about how relationships in their family have been affected by a child having a chronic illness. These perceptions and feelings include those relating to the dyadic relationship between a parent and their chronically ill child, with their partner (if there is one), with the unaffected children, between siblings and amongst all family members as a whole. Unlike the previous theme, the '*Family Dynamics*' theme reflects more general feelings about relationships, rather than being specifically linked to particular activities such as work or recreation.

The three sub-themes overlap to some extent, and some data were coded at more than one of these. The first sub-theme identified is '*Feelings about Family Relationships*', where parents referred to interactions within the family as a whole. This relates to how parents described how the 'extended' family and 'core' family functioned, related to each other and coped, and in some cases, how this changed as a result of the illness.

The second sub-theme relates to parents' perceptions of and feelings about 'roles' of particular dyads, in particular about parenting issues. Due to the complexity of this theme and to improve clarity, inclusion and exclusion criteria were developed during the coding process, as shown below:

What was coded as 'Feelings about parenting role'

- Feelings about parenting in general
- Supportive / encouraging behaviours towards child
- 'Treating as special'
 - Being very protective and not 'letting go'
 - 'Spoiling' – compensating for restrictions or due to feeling sorry for the child
 - Treating child differently from siblings

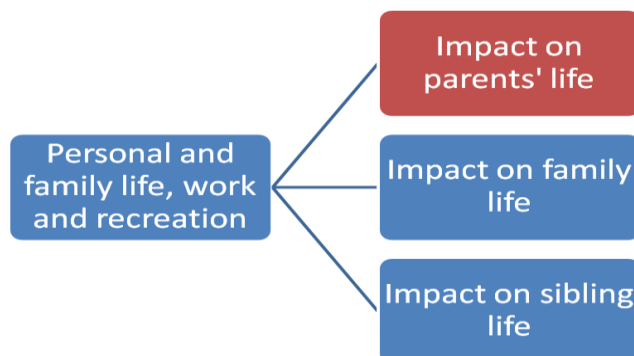
- Being uncertain or inconsistent in response to child behavioural issue (due to uncertainty of how to attribute behaviour – due to the disease, developmental stage or individual?)
- ‘Treating as normal’
 - Trying not to overprotect, allowing independence
 - Not ‘spoiling’
 - Encouraging openness
 - Treating child the same as siblings
 - Response to child behavioural issue is consistent and/or firm – no expressed uncertainty of attribution of behaviour

The next sub-theme, ‘Feelings about partner relationship’ was used to code data where parents described:

- The supportive role of their partner, and also how they in turn supported their partner
- Ways in which they each responded to or coped with stressful events and how this impacted on their relationship
- Sources of conflict and how these were resolved.
- How roles were decided upon and tasks allocated, and how this affected the relationship.

7.2 PERSONAL AND FAMILY LIFE, WORK AND RECREATION – ISSUES COMMON TO EACH DISEASE GROUP

7.2.1 Impact on Parent’s Personal Life



Parents in both groups discussed the impact of their child's illness on their personal lives in more depth than on family life. In both groups, certain influences of their child's illness or its management impacted on their personal lives (albeit in slightly different ways due to the nature of the child's illness or to a different extent). The illness or its treatment had a varying degree of impact on some parents' personal lives.

There were few aspects of parents' life that were specific to one group or the other (which will be discussed in Section 7.3). However, parents in both groups reported experiences in common in relation to the impact on their personal lives. Details may be found in Appendices 7.1 and 7.3. The following areas common to both illness groups will be discussed in turn:

- *Sleep*
- *Vigilance and monitoring concerning the child's health state*
- *Time, effort and features of treatment*
- *Feeling the burden of care or weight of responsibility*
- *Working life and /or potential working life (e.g. would have otherwise had a job or different job features)*
- *Financial impact*
- *Socialising / going out or going away with partner or friends*
- *Change of parent's lifestyle habits*

An interesting point to note, which will be illustrated in the following interview extracts, is that whilst parents from both groups reported experiences in relation to the above aspects of life, their responses often differed. This may be important, since it will be useful to highlight factors that might affect the impact of the experience.

Sleep: Asthma Group

Some parents from the asthma group (A_2, A_4, A_6, A_7, A_10, A_12, A_16) reported that their child either currently or previously woke frequently during the night. In most cases, this was when the child was more ill than usual, although in the case of A_16, it was ongoing. Some parents reported that lack of sleep affected their ability to give their best at work (such as A_4) or affected their mood and led them to feel 'run down', as in the illustration of A_7 below:

Respondent	Interview Extract
<p>A_7</p> <p>Parent has unplanned disturbance of sleep</p>	<p>M: And like at night time, when she's sleeping at night, she's really wheezy, and she coughs a lot and stuff. So you're up and down to her all night as well.</p> <p>I: So that makes you tired, really?</p> <p>M: Yeah. And I still have to be up at 7 to take the other one to school, and then stay still motivated throughout the day because of the other children needing me during the day. So... it does, after a few days... I can handle it for - I've been pushed to the limit when she's been unwell with how long I've gone without all that sleep. But it's got harder as the year's gone on, 'cause I've got an extra - I've got a baby now, and he gets up three times during the night. And it always works out that I'd just settle [child's name] back down, and this one (indicating baby) will get up for a feed. I'll settle him back, get into bed, and [child's name] would be up. In that respect, I can get very, very tired. But I don't mind doing it obviously. I wouldn't change the way I have to deal with it, but...</p> <p>I: But obviously it affects you, to be tired all the time.</p> <p>M: Yeah. It makes me more run down. And things then, I tend to think that things get on top of me, and it makes the day to day living hard. It really does. And I get down in the dumps and stuff. It then rubs off on the others as well, so...</p>

Sleep: Diabetes Group:

Although some parents of diabetic children also experienced sleep disturbances (D_2, D_4, D_5, D_6, D_12), it was usually planned (e.g. parent knew they would get up during the night to check a child's blood glucose), although occasionally were disturbed by the child having a 'hypo' (D_6). An example of this planned disruption to sleep is illustrated by the example of D_4:

Respondent	Interview Extract
<p>D_4</p> <p>Parent has planned disturbance of sleep</p>	<p>M: He's now on 4 units in the evening. That was when he was on 3, actually, when I was doing them [blood glucose readings during the night]. You know, so...</p> <p>I: So that affects your sleep somewhat, doesn't it?</p> <p>M: Well I mean if I get up naturally and if I'm coherent, you know.. I don't even think about it any more. You just do it by instinct. (laughs)</p>

	<p>F: You're like a cat on a hot tin roof.</p> <p>M: I'm NOT!! It doesn't bother me. I mean you're up at three in the morning, worrying about God knows what else. So, you know, I get up. It's not a big deal. (laughs)</p>
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These illustrations are typical of the experiences of sleep disruption of the two groups, which appears to generally have a greater impact on the personal life of the parents of asthmatic children.

Vigilance and monitoring concerning the child's health state: Asthma Group

Four of the parents of asthmatic children felt that the need to be extra vigilant, by monitoring their child's respirations, listening to their breathing or checking whether the child felt unwell had an impact on their personal lives.

Two parents thought this was the case only when their child was particularly ill (A_9, A_11), but two said that they always did this, and that they were always aware (A_6, A_16); this was possibly related to the child frequently having severe attacks. Other parents of asthmatic children also reported this sense of being 'on edge' or alert, but did not report this in response to a question about the impact of the child's illness on their personal lives. So perhaps the monitoring or vigilance was not associated with anxiety or worry and so they did not feel it impacted on their lives to the same extent as in the following example of A_16:

Respondent	Interview Extract
<p>A_16</p> <p>Always being vigilant and watching respirations</p>	<p>M: Well, you're always watching him, you're always watching him, counting and....</p> <p>I: I noticed you listening to his chest earlier. Do you do that quite a lot too?</p> <p>M: Yes, we count his breathing.</p> <p>...</p> <p>I How normally do you feel, as you do now.... like it sounds like it's not so bad, you take it in your stride, you just make these adjustments and it's not affecting you very much. Is that how you feel?</p> <p>M: The asthma?</p> <p>I: Yes.</p>

	<p>M: Well, you're always wary. I mean, you're always counting, watching him all the time, we are, [husband's name] and I. So, but that's been since he was two, so I don't think we know other way. And maybe we were more relaxed before the first attack, and then since then we watch, and we're sort of worried parents.</p> <p>I: You worry a bit more.</p> <p>M: We are. Maybe because we're older parents, we worry more, I don't know.</p>
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Vigilance and monitoring concerning the child's health state: Diabetes Group

Although all the diabetic children had complex treatment regimes and risks of effects of blood glucose disturbances, only three parents specifically referred to vigilance and monitoring as having an impact when questioned about the effect of diabetes on their personal lives (D_4, D_12 and D_13). So whilst they may be vigilant and monitoring, they might not see it as being very influential on their personal life. Perhaps this was because a diabetic child often recognises the beginnings of a 'hypo' and takes action either by telling someone they need carbohydrate, or by taking some carbohydrate themselves, before it becomes more serious. Also, blood tests are ideally done at regular periods, which the parent can anticipate and plan for. These factors perhaps help some parents to plan when they might work or go out. Clearly, if children have poorly controlled diabetes or unpredictable attacks, this might not be the case.

However, asthmatic children (particularly those with less good control) may have gradually worsening respiratory function without anyone noticing it (including the child). Therefore, the parent may feel they need to look more specifically and regularly for changes in respiratory function, so this may feel like a more significant factor influencing their personal life.

Only one parent in the diabetic group (D_6) specifically said that it did not significantly affect her personal life. A possible factor that might have contributed to this experience was that the child, now aged 6 years, had been diagnosed as an infant. Therefore, the parent had not needed to make significant adaptations later in the child's life. Also, this child had never been significantly ill with diabetes and had never been hospitalised.

In contrast to D_6, other parents (D_12, D_13) said that always having to be aware, alert and vigilant made them feel like diabetes 'ruled their lives'.

Respondent	Interview Extract
<p>D_12</p> <p>Needing to be vigilant takes over one's life</p>	<p>F: What still rings in my ears is (doctor's name) saying, 'You've got to rule diabetes, not let it rule you, which I thought at the time was a fantastic philosophy, but totally impractical, because it just doesn't work.' It takes over your whole life.</p> <p>M: It's with you every day. Every single day, breakfast, lunch, tea and in-between. It's a disease that never, ever leaves your mind.</p> <p>F: If you're a conscientious parent, it takes over your whole life.</p> <p>M: Yeah.</p>

It is perhaps relevant to note that the parents above had experienced a recent unexpected fright when their child had collapsed without warning; this could have contributed to their feeling of a need to be extra vigilant, in the same way as did the parents of A_16 above. Interestingly, the child of the other couple who responded similarly to D_12 (i.e. D_13) had been diagnosed just one year previously (unusual in this sample), so this feeling of a need for a high level of vigilance might have been more common in parents in this situation, as it was not yet 'routine'.

Time, effort and features of treatment: Asthma Group

Five parents in the asthma group (A_1, A_2, A_5, A_10, A_15, A_16) felt that time, effort and / or features of their child's illness impacted on their personal lives in the past or did so at present. Most of these parents referred to the need to be organised and to always carry medication with them; some discussed the time consuming or inconvenient nature of treatment (for example getting prescriptions or administering nebulisers).

Whilst acknowledging that such things affected life, parents generally accepted the necessity and it did not seem to have a very serious impact, as illustrated by the following excerpt of A_15, who described it as 'a pain' when going out to work functions, as she used to bring along her son and his medical equipment:

Respondent	Interview Extract
<p data-bbox="316 331 384 360">A_15</p> <p data-bbox="316 434 523 528">Time and inconvenience of preparation</p>	<p data-bbox="555 331 1422 595">M: I mean, when he was glued to his nebuliser, you couldn't even go out for a picnic. You know, unless you went out some place that had a plug, which was a bit of a pain in the ass, to carry this bloody big thing around with you and you had to sort of plan ahead. I mean we used to have work functions, like afternoon picnics, and barbeques, and we'd have to phone ahead, and ask, 'Do you have an electrical point, and is it accessible?' you know, before you agreed to go. So we don't have any of that now.</p>

Time, effort and features of treatment: Diabetes Group

It was more common for parents of children in the diabetic group to report the impact of extra time, effort and features of treatment on their personal lives (D_2, D_3, D_7, D_8, D_11, D_13, D_14, D_15), particularly when preparing to go out. An example of how most parents felt about the impact of the need to be highly prepared is illustrated by the following excerpt:

Respondent	Interview Extract
<p data-bbox="316 1249 384 1279">D_13</p> <p data-bbox="316 1417 523 1480">Time and effort of preparation</p>	<p data-bbox="555 1249 1414 1312">F: Like going out. Checklist before you go out. 'Have you got all your insulin, just in case we extend our stay out somewhere?' You know?</p> <p data-bbox="555 1350 1091 1379">M: It's like reverting to having a baby again.</p> <p data-bbox="555 1417 667 1447">F: Yeah.</p> <p data-bbox="555 1485 1035 1514">M: Taking the pram and everything out.</p> <p data-bbox="555 1529 592 1559">....</p> <p data-bbox="555 1552 1414 1648">M:...Like we went all the way out to [town's name] and she'd forgotten her insulin, hadn't she, that day? So we had to drive all the way back for, just before her dose time.</p> <p data-bbox="555 1686 1422 1883">F: We were visiting friends. And we were planning on staying the night, but in the end we had to turn around and say, well, I mean we could have probably gone down to the local hospital and done it, but at the end of the day, it's aggravation for them, it's aggravation for us, and all the rest of it. So, it was easier just to get back in the car, it's only two hours, but it disturbed the weekend, if you see what I mean.</p>

One parent (D_6) and one couple (D_5) responded that this need for advance preparation did not have such an impact, because they had always needed to be prepared in this way since the children had been infants. In these two cases, their child had been diagnosed during infancy.

Other parents in addition to D_13 above, all of whom were parents of adolescents diagnosed later in childhood, also reported that it was like ‘going back to having a baby again’ (D_3, D_8, D_14). It’s possible that needing to revert to an earlier phase of childrearing activity was harder for parents than maintaining the high level of preparation needed when children were younger.

A further point mentioned by one couple was the time consuming nature of always going to the chemist and having to take longer over food shopping because of the need to read ingredients on labels (D_8).

Feeling the burden of care or weight of responsibility: Asthma Group

Some parents in the asthma group reported feeling a burden of care or weight of responsibility for several reasons. One included feeling that most of the responsibility for the child’s care and treatment fell to them as a mother (A_2, A_4, A_5, A_12, A_14) either because it had been agreed between a couple that this would be the mother’s role, or the mother was separated or divorced, and the ex-partner was not available and/or not competent in the child’s care. This is illustrated by the following extract from the interview of A_4, who was a single parent:

Respondent	Interview Extract
<p>A_4 Adolescent girl Feeling the weight of responsibility</p>	<p>M: Yeah, there have been times, like quite recently, and when she was nine. And I’m sure there were times when she was a baby. At least at this age, I get some feedback, whereas as a baby I didn’t really. And you do feel, sometimes the responsibility of it is a bit enormous.</p> <p>I: Yeah, so you feel like you can’t hand it on to anyone else, or..? Or you feel like you can’t discuss it with anyone else to some extent, or...?</p> <p>M: I think sometimes I feel that I’m bothering the doctors a bit. I have to bother them all day through patients [in job as health professional], and getting an appointment can be difficult anyway, and so sometimes if she really is poorly, I’d just like them to say, ‘She’s poorly, let’s do x, y and z’. Let me not have to make those, almost make the clinical decisions. (sighs)</p>

This parent seemed to be particularly concerned about the responsibility of clinical decision making. Other parents expressed the feeling of having to always be responsible that everyone else was prepared with medication and treatment knowledge (A_2, A_12, A_14), or having to unexpectedly step in when a former partner could not cope with the child (A_5).

Feeling the burden of care or weight of responsibility: Diabetes Group

Similarly, many of the parents in the diabetic group expressed how the weight of responsibility affected their personal lives (D_1, D_2, D_7, D_12, D_13, D_14, D_15). Some parents described always having to be ‘on the ball’ to respond to health needs appropriately, feeling constrained or restricted because of the responsibility, or always having to make provision for the diabetes. An example of this is shown in an extract from the interview with D_2:

Respondent	Interview Extract
<p>D_2</p> <p>Feeling the weight of responsibility</p>	<p>M: Everything is different [after diagnosis] - nothing is ever the same again. And you are responsible for making sure that they are well, that their schooling is not interrupted, that they’re eating the right things, and that they’re injected with the right thing, that you don’t forget all the extra care - that you have to think about it when they go out to tea with friends, when friends come round to tea, when they go to sleep at night. And the more you go on, the more you realise it impacts life. You begin by them [medical staff] encouraging you, that you can get on and that nothing will change, but everything changes.</p>

Working life and/ or potential working life: Asthma Group

Some parents in the asthma group who had jobs reported that they experienced additional challenges such as finding appropriate childcare, being reliable in their working life when their child was unwell, and dealing with the aftermath of having taken time off work because of their child’s illness (A_4, A_5, A_12, A_13, A_15). Some of these consequences included the parent falling behind in their work and usually having to make up the lost time or lose annual leave. It was helpful when employers were understanding of the parent’s difficulties and need for time off (A_4, A_15), but others were not very sympathetic or tolerant of frequent absence, or did not seem to understand how serious the child’s illness was (A_15).

One parent felt worry and guilt about sending her child to school when unwell, and on top of this, felt unable to give her best at work because of this worry (A_4). Parents responded differently to these pressures, including reducing their working hours (A_5, A_12). The proximity of some parents' workplace to the child's school or hospital was important in helping them feel that they could maintain employment (A_4, A_5).

Other parents, some of whom had been previously employed, felt unable to look for a job. They gave reasons that it was too difficult or that there was no suitable childminder (A_2, A_11, A_13). One mother did not pursue a course to become a midwife, as she thought it would not be possible to commit to it:

Respondent	Interview Extract
<p>A_5</p> <p>Adolescent boy</p> <p>Effect of illness on working life and potential future career choice</p>	<p>I: So it hasn't affected your working life at all, in terms of having to take days off?</p> <p>M: Yeah. Yeah, because obviously if he has an attack and he has gone in... roughly he goes in one to two times a year, so if I'm on a shift pattern then say I have to be with him on the [ward's name], or I can, because he's older now, go to work and they'd call me out if need be, because I'm on site anyway. So, it's not too bad.</p> <p>I: So it's a bit easier now that he's older.</p> <p>M: Yes.</p> <p>I: You don't have to be there all the time.</p> <p>M: Yeah, I think it's all age-related. When he was young, there was no way I could leave him. I had to be with him. And when he was young, I only did work six hours a week anyway, so it was minimal.</p> <p>I: So, you work a bit more than that now?</p> <p>M: Yeah, yeah. As he got older, I could go. The only thing I can remember about his asthma really was I tried to do a college course, and I had quite a lot of time off because I had to keep obviously going out to be with [child's name], or being in hospital with [child's name]. So, I didn't, I couldn't do the college course. So did it affect my life? I'm sitting here saying, 'No', but when I look back and think of things like that, when I was on a college course, yes it did.</p> <p>I: So, was it towards a qualification, was it, your college course?</p> <p>M: Yeah, yeah. I had so much time off because of it.</p> <p>I: So you would have pursued a different career, perhaps?</p>

	<p>M: Yeah, oh yeah. I did want to, but it wasn't, I couldn't leave [child's name]. I couldn't. Yeah, looking back. I always wanted to do my midwifery, and I couldn't do it. I couldn't leave him, I couldn't.</p> <p>I: How do you feel now? Does it bother you now?</p> <p>M: It bothers me that I never did do it and I think it's too late for me to be doing it now anyway. I know that sounds silly, but perhaps it is because I've gone out of education. At that time, I was trying to be in education, but I've gone out of education now, so it does take a lot to go back into it again, what, for a third time.</p>
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The reasons given by these parents in the asthma group for taking different job choices or not taking job or career pathways seemed to relate to the fact that their child was frequently unwell, and parents felt unable to make the commitment of increased working hours or personal study.

Working life and/ or potential working life: Diabetes Group

For parents in the diabetic group, this was not apparently related to disease severity, but possibly because more regular and specialist treatment was needed during the day (particularly injections and blood tests), which were not able to be administered by some childminders, school staff or nursery care workers. In all, 13 parents described an impact of the child's illness on their working lives. Some parents said they temporarily stopped and then reduced their working hours (D_2, D_16), took a job with greater proximity to the child (D_3, D_4 (mother), D_5, D_10), became self-employed (D_4, father), stopped working altogether or did not restart working (D_1, D_8, D_9, D_11, D_15). In these latter cases, even if it would have been possible for someone to have administered injections, parents did not always trust those responsible for the child's care to safely look after them, and therefore felt it was the best decision not to seek employment.

The parents who continued working (even if in different jobs or with reduced hours) sometimes reported that the quality or enjoyment of their time at work was affected. For example, one parent described an unsympathetic employer and workmates who did not understand the pressure they experienced (D_12), as expressed below. On the other hand, some parents reported feeling well supported by their employer and workmates (D_3, D_7), or felt more relaxed because the person responsible for the child was trusted (D_4). Some parents (including D_12 below, and also D_2 and D_7) found it necessary to take time off

when their child was ill and for clinic appointments, but then had to make it up, so losing annual leave.

Respondent	Interview Extract
<p>D_12</p> <p>Making up lost working hours, unsympathetic employer and workmates</p>	<p>M: Yes, but I have my work as well. Like I've been off the last couple of days, and although [husband's name] does take a share in that role, he hasn't got to explain to anybody because he's his own boss, he hasn't got to explain to anybody why he's off. And I've had ten days off work this year, just because of [child's name]. And they're hours that I've got to make up. So that's quite stressful.</p> <p>I: So they don't give you any compassionate leave or anything like that, when your children are ill?</p> <p>M: (Shakes head).</p> <p>I: So that's quite difficult. So do you work full time?</p> <p>M: Nine 'til 3:30.</p> <p>I: It's still a full day isn't it?</p> <p>M: Yes, a pretty long day, really, more or less full time really. That's, that I find that quite stressful.</p> <p>I: Yes, to have to tell people all the time...</p> <p>M: Hmm, and to explain it, and justify it, again, because of their ignorance, it's that they don't understand.</p>

Another parent's enjoyment of work was affected as she worried a lot at work about whether the child was alright when the child was in nursery (D_4, mother). She did not trust the staff to care safely for her child. For some parents (D_2, D_9), less worry and / or more enjoyment was felt at work as the child grew older, and able to take more responsibility for their treatment or attend clinic by themselves.

Financial impact: Asthma Group

Two respondents discussed the financial impact of their child having asthma (A_5, A_7). They commented on the costs of extra treatments, change of housing, loss of earnings (due to needing time off) and costs whilst in hospital. One parent (A_5) said that finance had been a significant worry until a nurse had informed her about the disability allowance, which when awarded, had helped to reduce the parent's stress.

Financial impact: Diabetes Group

Parents in the diabetic group also described the financial impact on their lives, such as extra expenses including for ‘emergency’ meals when out, or extra shoes (D_2, D_8). One parent said they had chosen to send their child to a private school because they felt that teachers wouldn’t notice if their child became ill in a large class in the local state school (D_11). As with the asthma group, parents were grateful for the disability living allowance.

Socialising / going out or going away with partner or friends: Asthma Group

Many parents in the asthma group felt that they had a limited ‘social life’ either now or in the past, because of the child’s asthma (A_4, A_7, A_9, A_13, A_15, A_16). In two of these cases, the restricted social life was mainly when the child was not well (A_7, A_9), as illustrated below:

Respondent	Interview Extract
A_7 Restricted socialising when child is unwell	I: So how much do you think [child’s name’s] illness affects your personal life? M: ...If [child’s name’s] ill, I won’t take her out. I keep her indoors. And like if we’ve planned to go shopping, we can’t do it. And if I’ve planned coffee mornings with my friend, and [child’s name] is unwell, I won’t drag [child’s name] out, because I think it’s unfair on her. So I miss out in that respect. I wouldn’t change that for the world. No, I really wouldn’t. I don’t mind that, but yeah, it does quite a lot.

The main concern of respondents seems to have been lack of availability of appropriate childcare. If trusted relatives or friends were available to look after the child, this enabled them to go out with their partner or friends. Some parents referred to avoiding smoky environments (as the smoke clings to their clothing), which restricted socialising with some relatives (A_1, A_2, A_3).

Parents varied in terms of whether this restriction was a disappointment or not. For example, the respondent in A_7 above did not seem to mind the restriction too much, even though her social life was somewhat affected. Others reported that since they hadn’t had much of a social life before diagnosis anyway, it didn’t make much difference having a child with asthma (A_3, A_4, A_6, A_11).

Socialising / going out or going away with partner or friends: Diabetes Group

Similarly for the diabetic group, socialising with friends was an aspect of life that some parents felt was restricted (D_1, D_5, D_9, D_10, D_12, D_16). As in the asthma group, a key reason was lack of appropriate childcare. Also, social activities often needed to be organised around injection times if the babysitter couldn't give an injection. For example, D_10 said that she and her husband would usually be the first to leave a party in order to get home in time for an injection, which made her feel different from her friends with similarly-aged children, who did not have to rush home early.

A number of these parents said they would have liked to have had a weekend away with their partner (D_1, D_3, D_10, D_11, D_14), but felt they could not do this, although one couple had gone away on two previous occasions when their child was at a diabetic camp (D_3). The reason for not having weekends away was usually because there was nobody to give the child injections; in two cases the couple didn't go away because the respondent anticipated it would not be enjoyable (as they would feel 'on call' or worried) (D_3, D_16). One single mother (D_9) who did go away for a week without her daughter said that she felt anxious and guilty whilst away, and phoned home very frequently. However, this parent and one other (D_16) said they were feeling more comfortable about going away now that their children were older.

Bad experiences of things not going to plan on one occasion stopped some parents from trying again (D_3, D_10, D_11), as exemplified in the following excerpt:

Respondent	Interview Extract
<p>D_10</p> <p>Restrictions in weekends away as a couple</p> <p>Feeling preoccupied in always thinking about child's health or treatment</p>	<p>M: There was another episode a couple of years after, when we went away and then he was ill, and of course everything went out. But that was when [husband's name's] Mom and Dad were looking after [sibling's name] and [child's name] here. That was the first time, and he went and got this sickness thing, so that was... So then it was the guilt, we shouldn't have gone away. It seems as though every... you know, we'd just gone away, and that had to happen.</p> <p>I: So, did [husband's name's] parents have to take him to hospital, or was he OK at home?</p> <p>M: He was OK at home, but they were struggling to know what to do, because actually [child's name], I think, was trying to do it on his own a bit as well, and not worry them. It was a worrying time, but now he's got a bit older, he is beginning to take more responsibility.</p>

	<p>I: So, is that the only time you actually left him, to go away for a weekend or something?</p> <p>M: Yeah, we haven't done it since. We're thinking of doing it again soon (laughs).</p> <p><i>The respondent later discussed her feelings about making adjustments in personal life:</i></p> <p>I: Does it bother you that you have to make these adjustments, or not particularly?</p> <p>M: It does sometimes, when you're out enjoying yourself and he's in the back of your mind all the time. You don't, you know, you never forget it, because it's ongoing all the time.</p>
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Having opportunities for leisure without worry is clearly important to parents. Additionally, socialising with friends can help develop meaningful friendships, important in gaining support on an emotional level. One couple (D_12) described how friends were important as they had no close family. Evidently this emotional support from friends was felt to be lacking for these respondents:

Respondent	Interview Extract
<p>D_12</p> <p>Feeling resentful about restrictions in personal life</p> <p>Not feeling that have friendships that enable emotional sharing</p>	<p>I: So how do you feel about these restrictions on your life, you know, like you were saying about going out?</p> <p>M: It gets you down.</p> <p>F: Resentful, yeah, very. Very resentful, it's nothing, but inevitably there's nothing you can do about it, and you console yourself with the fact that, yes, she's still here, she's relatively healthy, she's not leading an abnormal life as such, she's got sort of a small amount of special needs. Um, there are a lot of parents a whole lot worse. So we've got enough people to speak to [about diabetes], but what we don't have...</p> <p>M: Not on the emotional side.</p> <p>F: No, that's what I was going to say, is anybody to bounce feelings off, that we know well enough.</p>

Only one parent (D_6), who has been referred to previously in this Chapter, felt that her social life was not restricted because she said she was always determined to find a way around a problem in order to still have an active social life. More than once in the interview, she said

she refused to use diabetes as an excuse not to do things. In one incident, she taught her reluctant eldest daughter to give injections so the couple could go out, and in other cases the couple took their diabetic daughter with them when going away for a trip. This is an example of how parents who face essentially the same hurdles sometimes respond to them quite differently.

Change of parent’s lifestyle habits: Asthma Group

Two parents in the asthma group who were smokers commented that they no longer smoked in the house because it was detrimental to their child’s health. One parent expressed a wish to quit (A_7), whilst the other found smoking helped her to cope (A_2) and did not express a motivation to quit smoking. A parent whose son had mild asthma (A_10) started to exercise more with her child, to ‘strengthen his lungs’. Generally, these small changes were viewed as positive for the child but parents did not mention the health benefits for themselves.

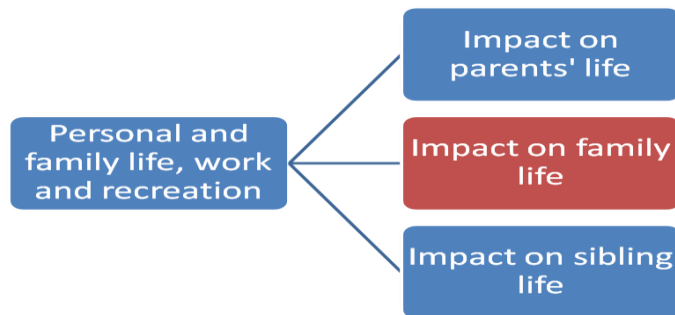
Change of parent’s lifestyle habits: Diabetes Group

For the diabetic group, change of parents’ lifestyle generally related to diet. Whilst some parents said they did not change their diet at all after diagnosis (D_7, D_15), or ate foods less appropriate for the child when they were out rather than at home, as they had done previously (D_8, father), others said they adjusted their diet and/or mealtimes to be similar to the child’s (D_8, D_9, D_10, D_12). This was to have more regular mealtimes, so not skipping meals (D_10, D_12), and eating different types of food such as more carbohydrate and vegetables (D_9, D_10). One parent (D_10) said she bought a lot more food than formerly, to be sure of not running out:

Respondent	Interview Extract
D_10 Diet, mealtimes and food shopping changed	<p>I: It sounds like...you just kind of had to be more organised, I suppose, and plan more I guess, is what you are saying.</p> <p>M: Yes. I feel as though I shop every day. I probably buy too much, and have become an obsessive food shopper really as well. (Laughs).</p> <p>I: You try and get too many things in the house, do you think?</p> <p>M: Yeah. I’m always throwing stuff out because I have to make sure there’s plenty in, and probably don’t need that amount, but it’s something I feel I have to do. (Laughs).</p>

	<p>I: You still find you do that?</p> <p>M: Yeah, because you're continually trying to.... You see, he's very thin as well, and I think he'd like to bulk up more, but I think well, he never puts on any weight, with all that activity but you're continually trying to find different things to keep him... he never was a very good eater, even before he was a diabetic. He wasn't really interested in food, so that was a struggle to keep him constantly...different things that he would eat. Yeah, and I'm always, even now, trying to feed him different meals and I think probably more so than I would normally.</p> <p>I: Do you think you changed your diet very much, after [child's name] was diagnosed, and your family diet?</p> <p>M: Yeah, well, our diet revolves a lot around carbohydrates, which obviously as a sports person he needs even more, but then we [respondent and her husband] put on weight, from eating all the bread he's eating.</p>
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7.2.2. Impact on Family Life



Parents from both illness groups discussed aspects of their family life that were affected by the child's illness. Further information may be found in Appendices 7.2 and 7.4. To recap, activities of family life included those that involved all family members including siblings and possibly extended family members. The aspects of family life common to both groups were:

- *Impact on family holiday or leisure experience*
- *Impact on family lifestyle, in relation to changes in activity or food*

The first of these, 'Impact on family holiday or leisure experience', will be considered in this section. However, as the impact on family lifestyle typically evoked particular sibling responses, this aspect of family life will be discussed under the sub-theme of sibling

responses. The experiences of the asthma group and then the diabetes group will be discussed.

Impact on family holiday or leisure experience: Asthma Group

A number of issues were reported by parents in the asthma group about the impact on the family's holiday or leisure experiences. These fell into three broad categories:

- *Restriction in choice of location of holiday or leisure destination* (e.g. not far from a hospital and medical expertise, absence of known allergens likely to trigger attack, availability of travel insurance coverage for the child) (reported by A_5, A_6, A_8, A_11, A_12, A_13, A_14, A_15, A_16)
- *Curtailing or cancelling holidays or leisure activities due to the child's illness* (reported by A_4, A_6, A_7, A_9, A_12)
- *Detailed advance preparation* (e.g. time for finding suitable destinations) (reported by A_8, A_13, A_16)

In relation to restrictions of choice of holiday or leisure destination, not all parents found this restriction to be disappointing. In two cases, (A_5, A_11), the child was actually less prone to asthma attacks when abroad in countries with hotter climates. Therefore, although still restrictive, the consequences may have had financial rather than holiday enjoyment limitations. However, the following example of the impact of restricted locations is more typical, and also illustrates the second area discussed by some parents of the impact of curtailing holiday or leisure activities when the child was ill or had recently been ill, which was often associated with feelings of disappointment as in the case of A_12, whose son's asthma severity had recently increased:

Respondent	Interview Extract
<p>A_12</p> <p>Restricted holiday destinations, curtailing options when child recently unwell</p>	<p>M: As a family, as I said before, asthma didn't change anything that we did or you know, or whatever. Whereas now, this year, we've swapped all our foreign holidays to UK holidays; I don't think we'll probably leave the country for a long time. A long time. And my husband is nervous of leaving the county of Oxfordshire, you know. And all that's a totally new experience for me, to be living in the shadow of something.</p> <p>I know some of the things we've put in place, like not traveling to foreign countries, is probably quite sensible, and one that (doctor's name) agrees with. But you just think, it's such a shame, because financially we've got the money to travel abroad. We've got two totally</p>

	adventurous, otherwise healthy children. There's lots to see and do that we'd sort of set our sights on, and certainly for the next couple of years that's probably not a sensible thing to do. So I think that's been the hardest part of the recent sort of asthma episode that he's had.
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In terms of frequently having to plan well in advance, points were raised such as trying to find holiday insurance coverage, getting steroid and antibiotic drugs in advance, in case of attacks, learning key medical words in the local language and finding the location of medical care. These types of factors are illustrated in the following excerpt of A_14, who discussed some of these in the context of describing her child's asthma attack whilst on holiday, which had probably been triggered by excitement and exercise:

Respondent	Interview Extract
A_14 Needing to prepare in advance for risks on holiday	<p>M: We were on holiday in Kefalonia; I don't know if you've ever been, but I mean it's only for the fit. The hills would kill you, and it very nearly did. It got to the point where we had to get taxis everywhere, because we just couldn't get her up the hill. She got quite distressed.... But that [attack] was unexpected, because normally it would be, 'OK, just have couple of puffs of Ventolin and then you'll be fine', but she wasn't. And then you start thinking, 'Oh, my God, where's the nearest hospital?' 'What's the language barrier? How are we going to get her covered?' I mean, trying to get insurance for her, for holidays, is difficult, because they say to you, 'You can go on holiday, but if she has an asthma-related incident while she's away, you're not covered'. 'Oh, right, OK then'. Yeah.</p> <p>I: Oh dear. So has it stopped you from thinking about going away, or...?</p> <p>M: No, originally we used to go prepared with oral steroids, and antibiotics, just in case you know, something flared up. And my GP was excellent, always gave me steroids and said, 'You use..', well, when I say the GP was excellent, the consultant was excellent in writing to the GP and saying, 'This family must have a supply of Prednisolone in the cupboard. They must have antibiotics, so that they can hit it at the first sign of trouble'. Because it was always in the middle of the night, and you know, who do you get in the middle of the night?</p>

In one case (A_5), different family members went to different holiday destinations; for example, on one occasion the siblings went to visit relatives abroad, and asthmatic child stayed at home with his mother. The respondent felt that the family missed out on taking holidays together. She reported that the child's siblings found it difficult to be away without

their mother, and hard to understand. In other cases, temporary illness of the asthmatic child meant that leisure activities such as family outings were cancelled.

The main restrictions that permanently affected decisions about leisure destinations seem to have been the inability to visit places with animals, such as the zoo or horse riding schools (A_5, A_8, A_11, A_13, A_15, A_16), or restaurants or enjoying home cooking of fish or eggs, due to allergy risks (A_8, A_11). With the exception of A_5 referred to in the previous paragraph, parents only reported sibling responses of acceptance (A_4, A_6), although parents themselves sometimes expressed sadness or disappointment about the restrictions.

Impact on family holiday or leisure experience: Diabetes Group

In the diabetes group, some of the same broad issues as in the asthma group were reported by many of the parents:

- *Restriction in choice of location of holiday or leisure destination* (D_3, D_4, D_5, D_11, D_12, D_13, D_14, D_15).
- *Detailed advance preparation* (e.g. time for finding suitable destinations) (D_3, D_5, D_12, D_15).

Eight parents (indicated with the first bullet point above) described restrictions in choice of holidays, usually on the type of holiday accommodation rather than destination. Some parents talked about needing to choose somewhere with a refrigerator to store insulin, that they eliminated options requiring plane travel across time zones to avoid risks of blood glucose problems, stayed in self catering in order to control food and mealtimes, or in a holiday complex in town rather than villa in the country, so as to be closer to medical facilities in an emergency.

Some parents described the negative aspects of planning for or experiencing holidays, such as the time needed to organise more things in advance such as learning medical words in a foreign language or finding out hospital locations (D_3, D_5, D_15), the need to get additional travel insurance (D_12), or worry about access to appropriate food at correct times (D_10, D_11).

A few parents commented positively on the help received from clinic to manage insulin dosages and so on during plane travel. One parent described positive aspects of the diabetes

on holiday, explaining that they could go to the front of the queue on the ferry (D_6). Other families still chose to go to holiday destinations that they knew from experience would pose challenges in the control of the diabetes, but went anyway (D_5, D_10, D_12). When discussing holidays, these parents said they had just ‘muddled through’ (D_12), had worried a lot about risks (D_10) or felt pleased because the child’s blood glucose control had been better than earlier experiences on holiday (D_5).

The following excerpt illustrates a number of these points, showing some of the challenges and feelings about coping with holidays:

Respondent	Interview Extract
<p>D_10</p> <p>Challenges of holidays, learning from experience over time</p>	<p>I: So did it affect anything else in your family, like holidays, or anything like that particularly?</p> <p>M: No, we went on holiday that first summer [after diagnosis] with some friends to France, but I remember there was a cottage, sort of in a quiet little French village, and we seemed to be driving forever, and then I had this awful, ‘Oh where’s there going to be a shop?’ (Laughs). I’m not going to be able to get him any food’, this sort of horrible feeling, because you try all these sleepy little places, but of course as usual in France, you get to these little places and they’ve actually got nice little town centres with all these nice restaurants and shops open, so...even though we were driving through bits I was thinking, ‘I’m not going to be able to find anywhere to buy him food’. It was fine, but still a worry. And it was hard to manage. Blood sugar seemed to be all over the place because of all the different routine.</p> <p>...</p> <p>I: So did that change the kind of holiday you went on afterwards, because it sounds like it was kind of a bit more unpredictable, maybe?</p> <p>M: Yeah, when we came back from that holiday and then his blood sugars seemed to go sky high and take a couple of days to...that was upsetting again, because I thought, ‘We can’t, we just can’t do anything out of the ordinary. Everything’s OK if you’re plodding along with school life, and then you go and try and to something different and it all goes haywire. But we just did that type of holiday with friends for the next few years, but this year we did go to America because we wanted to do that again, and hadn’t done that since before it happened, and we wanted to take... but it was going to be quite a big deal. We felt that was going to be difficult, so it was only this year we got around to it. We did that, and it was difficult (laughs).</p> <p>I: So you had kind of more like, package holidays where everything was predicable rather than touring holidays, which were less predictable.</p> <p>M: Yeah. We’d have probably done more.</p>

	<p>I: So the subsequent touring holidays were OK, though, he was still alright after then?</p> <p>M: Um, yeah. It was OK, you just get to know more what to do. We know that it's, well you just learn as you go along, you know that when he's travelling now, because he's such an active boy all the time, as soon as you travel, going anywhere, even on an aeroplane, you know that he's, if you give him the same amount of insulin, and he eats the same amount, he's going to go high because he's not using that, being as active, so you learn to do things accordingly.</p> <p>I: So that first one was a bit hard, but the other times after that were OK?</p> <p>M: Yeah, they got easier, and I mean, it was a bit more difficult again, going to America this year.</p> <p>I: What, in terms of all the advance planning and everything you had to do?</p> <p>M: Well yeah, just with the timing you know. The hospital give you a sheet, for varying the time change, what to do about it, but it still seemed to go a bit haywire. When you read it, it all sounds so straightforward, but you get to America, and they give you such big breakfasts! (Laughs). Anything like that obviously puts it all out of, so without realising he was going to eat such a big breakfast like that, obviously the next day, that meant giving more insulin, but... Yeah, it just seemed, it's a challenge. A bit of a worry, but we had a good time.</p>
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Impact on family lifestyle, in relation to changes in activity or food – Asthma Group

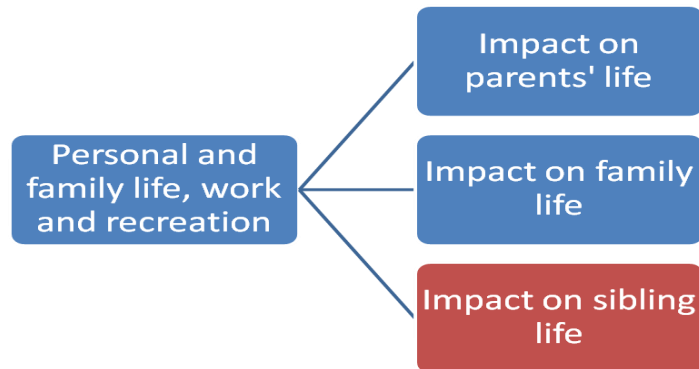
In the one case where the child had mild asthma (A_10), the impact on family life was positive. After the child's diagnosis, the whole family took up swimming (to 'strengthen the child's lungs'), were generally more active and started eating 'more healthily'.

Impact on family lifestyle, in relation to changes in activity or food – Diabetes Group

Parents in the diabetes group also discussed the impact of the child's diabetes on family lifestyle, mainly in relation to more structure at mealtimes and change of diet within the family (D_2, D_8, D_9, D_10, D_12), although some families did not change in this respect (D_6, D_7, D_14). Some differences were noted in terms of having sweets in the household. One family did not allow any sweets in the house, didn't offer sweets to visitors and stopped them from bringing any to the house (D_12). However, the parents saw this as a positive

change, as it helped the family to eat more healthily, even though they experienced some problems with the younger sibling not being allowed snacks. This will be discussed in the next section on ‘sibling responses’.

7.2.3 Impact on Sibling Life



To recap, this sub-theme only relates to data where sibling behavioural responses were reported, rather than reciprocal interactions with siblings (which will be discussed under the ‘family dynamics’ theme). Further information may be found in Appendices 7.5 and 7.6. The common issues raised by parents from both groups were:

- *Sibling reactions to witnessing attacks or hearing distressing information*
- *Sibling involvement and responses to assisting with medical care of child*
- *Sibling reactions to differences in time and attention given by parents (equal or unequal treatment)*

Sibling reactions to witnessing attacks or hearing distressing information – Asthma Group

One parent (A_12), whose son was severely asthmatic and daughter (sibling) was mildly asthmatic, described how her daughter had witnessed a recent severe asthma attack of her brother that required hospitalisation. Since then, the parent said that her daughter had become more ‘clingy’ with the parent and more ‘cuddly’ with her brother. The mother interpreted this behaviour as being motivated by anxiety and worry about the possible death of her sibling. Similarly, a couple (A_13) described how their five-year-old daughter had been told by a child cousin that people can die with asthma. Since then, the parents said that their daughter

had expressed worry about whether her brother would return from hospital each time he went, and had shown more ‘cuddly’ behaviour towards her asthmatic brother.

Sibling reactions to witnessing attacks or hearing distressing information – Diabetes Group

In the diabetic group, a number of parents reported that the siblings showed distress when hearing of the child’s diagnosis or after witnessing a bad hypo (e.g. seizure, unconsciousness) (D_1, D_3, D_4, D_8, D_13), with some subsequently becoming more protective (D_1, D_3, D_12). Other reactions following the event included feeling more sorry for the sibling, or going back to treating the sibling as before, after a brief such period (D_8). The parents of D_12 discussed how the experience had been very powerful for the two siblings who had witnessed it, with one still talking about it, although the experience had occurred years previously. One sibling (of D_13) apparently tells his friends in a matter-of-fact way that his sister would die without insulin, but shows no overt distress.

Sibling involvement and responses to assisting with medical care of child – Asthma Group

Siblings in both groups were involved to varying degrees in the medical care of their chronically ill sibling. In the asthma group, this included reporting to the parent if the child was having breathing difficulties, getting the child’s nebuliser or inhaler for them, turning on and administering a nebuliser or helping a child keep calm during an attack (A_5, A_6, A_12). Although other parents did not report that the siblings helped, it is possible that more siblings were involved, but as treatment for most children just involved taking inhalers, there may not have been much opportunity for siblings to be involved. Where sibling additional responsibilities were reported, the siblings seemed to accept them.

Sibling involvement and responses to assisting with medical care of child – Diabetes Group

Many more of the siblings in the diabetes group were involved in medical care, such as getting a sweet when their sibling was feeling ‘hypo’, administering or helping with administering injections (or distracting the child during this time), testing their blood glucose levels, helping a child to work out their food requirements at lunchtime when at school, and volunteering not to have sweet things on occasions when their sibling was not allowed them (due to too high blood glucose) (D_1, D_2, D_3, D_4, D_5, D_6, D_10, D_12, D_15, D_16). Some siblings injected themselves to experience what it was like to have an injection (D_3, D_12). Whilst most siblings were competent in helping with medical care, and were

described by parents as ‘mature’, one sibling who had a difficult and often conflictual relationship with her diabetic brother (D_15), only helped (according to the parent) when ‘in the mood’ to do so, and at some other times acted in a way that was detrimental to the child’s health. Where siblings were helpful and cooperative, this appeared to be a support to parents.

Sibling reactions to differences in time and attention given by parents (equal or unequal treatment) – Asthma Group

Three respondents from the asthma group (A_5, A_7, A_14) said that they had to give less time and attention to the siblings than to the asthmatic child, especially when the asthmatic child was in hospital or very unwell. They felt that they also treated the children differently, with sometimes the sibling complaining that the parent showed a preference. Two of these parents reported that siblings were resentful of this apparent preference (A_5, A_14). One of these siblings, now a teenager, continues to smoke, despite knowing it is detrimental to her asthmatic brother’s health. Finally, one respondent said siblings seemed unaware of the extra time, attention and preference given to the asthmatic child, and didn’t complain (A_7), perhaps because they were quite young and less aware.

Other asthma group respondents said that although they needed to devote more time and attention to the asthmatic child, they did not treat their children any differently (A_9, A_10, A_12, A_13); however in two cases, the parent said the sibling did not agree that this was the case (A_9, A_10).

Sibling reactions to differences in time and attention given by parents (equal or unequal treatment) – Diabetes Group

Some parents in the diabetes group reported that they treated their children differently, particularly with regard to having sweets and snacks, for example allowing the diabetic child to have an evening snack, but not the sibling (D_12), not allowing siblings to have them when the diabetic child couldn’t have them due to their high blood glucose (D_5, D_7), or allowing sweets for the sibling only when the diabetic child was not present (D_2). One couple, on the other hand, applied the same rules to all their children, i.e. never allowing sweets at all in the early days post-diagnosis (D_10) or long term (D_12). Two respondents said there was no restriction on the siblings to have snacks and sweets (D_5, D_7). The following two excerpts illustrate these different perspectives:

Respondent	Interview Extract
<p>D_12</p> <p>Changing family eating pattern and fewer sweets is viewed as positive for family health, although had some difficulty with sibling wanting snacks</p>	<p>I: In what way do you [have a change]...?</p> <p>F: Um, freedom of what they can have to eat, for example, and considerations towards [child's name]. I mean the day before [child's name] was diagnosed, we'd been to the pictures. We had a massive Pick 'N Mix, loads and loads of sweets. It wasn't the norm (laughs), not frequently, but we wouldn't have stopped doing it if it hadn't been for [child's name] diagnosis.</p> <p>M: Yes, going to the pictures was a family special event, so that was all part of the special event, but of course that doesn't happen now.</p> <p>Older sibling: A bag of peanuts instead.</p> <p>F: If one of these two [unaffected siblings] we were out with us and they said, 'Can I have some sweets?', or something, then now we'll say 'No.'</p> <p>M: It's better isn't it, for their teeth. (laughs)</p> <p>F: They'll not have any fillings at this rate.</p> <p><i>Parent describes difficulty when diabetic child needed a snack at bedtime, and brother wanted one too.....</i></p> <p>M: ...Our son used to think that that was his ticket to have something as well.</p> <p>F: He'd go and get something.</p> <p>M: Yeah, and we didn't agree with that, and that caused problems, because it was like you were favouring a child over another.</p> <p>F: Yes. He would always want...she would like to have a bag of crisps, for instance, as a bedtime snack, which is not ideal, but it's a bit of carbohydrate. So... and then he would want one as well. And you'd find yourself thinking, 'Well...'</p> <p>M: 'You don't need a packet of crisps.'</p> <p>F: 'No, you don't need it. You're not going to starve without it.' But then you're thinking, on the other hand, 'Well, if you don't let him, then it's looking like she's got away with something that...'</p> <p>M: ... he wanted. So it has caused problems in that respect.</p>

Other parents allow sweets for the unaffected siblings, but the diabetic child might have to save her sweets for the end of a meal, or when the blood sugar is not too high, as expressed by D_6:

Respondent	Interview Extract
<p>D_6</p> <p>Family eating patterns not changed, siblings still have sweets</p>	<p>M: We have definitely no less sweets in the house; we just all hide in the passage. (laughs) Or in the cupboard. They have just as many. Nothing's changed.</p> <p>I: Your other children have the same food as they used to.</p> <p>M: Oh God yes.</p> <p>I: You don't have different food or anything like that.</p> <p>M No.We don't have a very sweet tooth in this house. No, I mean we never had sweets near us anyway. We still – well I say never, we never have them normally – but holiday treats. So I'll still take things like Sugar Puffs and then [child's name] will have a few, in what we call her more normal cereal. So they don't go without that, or they didn't have it anyway. No. We have ice creams when we're out. Sometimes now even I'll say to [child's name], 'Look, they can have sweets. I wouldn't if I was you'. And she might have a comic instead. So no, I don't think it makes any difference.</p> <p>I: So you organise the treats differently, basically really.</p> <p>M: Sort of.</p> <p>I: And [child's name] doesn't really mind that.</p> <p>M: Yeah, she might look a bit fed up, but only in a way you'd say to a child anyway. Well, you know, there's all sorts of things that they don't like isn't there? So she may look a bit sorry for herself, and I'll say, 'Well don't be so silly', you know. 'You can have a comic or other things'. She does get other things sometimes. I'll say, 'Go on [child's name], because you can't have this that or the other'. No, she's not hard done by. And she's got a tin. The other thing she does, like yesterday for example, they did go to the sweet shop. So [child's name] goes, and I'll say, 'Buy whatever you want. Eat a few, and then put them in your tin. And she's got a little tin, a sweet tin. So very often she gets the last laugh, because after supper, no one else has got anything, and she'll say, 'Can I have something from my tin?' So she'll gloat. (laughs). So it's swings and roundabouts, you know.</p>

Parents who did not restrict (or minimally restricted) sweets for siblings may have felt that this would mean the siblings would not feel unfairly treated. Interestingly, the parents of D_12, who did not allow sweets for any of their children as treats were also those who had persuaded the siblings to inject themselves to feel what it was like. It seemed to be important

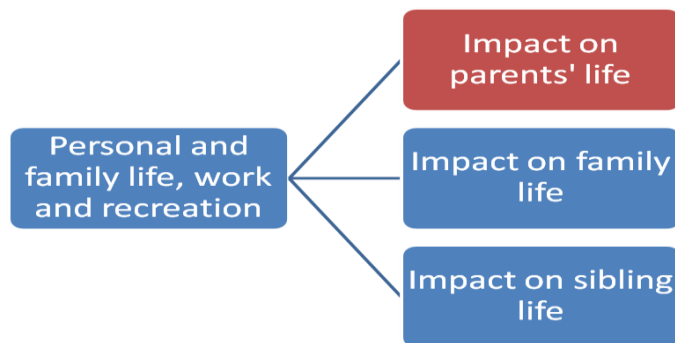
to these respondents that the whole family showed empathy in such ways. Caring behaviour was shown by a number of siblings, for example by questioning parental decisions that could affect the diabetic child's health (D_3) and showing a willingness to take responsibility for care management (as discussed earlier).

Sibling resentment was reported by only one parent because of their apparently unequal treatment, (D_15), and briefly by the sibling of D_10 when the parent had initially restricted sweets for both the sibling and the diabetic child.

7.3 PERSONAL AND FAMILY LIFE, WORK AND RECREATION – ISSUES UNIQUE TO EACH DISEASE GROUP

Unique issues were identified in two of the three sub-themes relating to the above theme. These concerned the impact on the parent's personal life and on sibling life. Therefore, there will be no reference in this section to the third sub-theme, impact on family life.

7.3.1 Impact on Parent's Personal Life



Asthma group

Some parents of asthmatic children indicated that they needed to do extra housework or change their living environment such as removing carpets or curtains to minimise house dust mites (A_3, A_5, A_7, A_8, A_12, A_16). However, parents generally did not seem to mind this, particularly if they felt it reduced their child's asthma. Some of these parents also mentioned occasions when they felt restricted in going out of the house due to their child's ill

health, for example shopping for food, or felt they needed to hurry back home if out (A_2, A_4, A_7). This issue only had an impact when the child was unwell.

This issue of stressors being particularly high for parents of asthmatic children with recent serious, life-threatening attacks was evident in the effect on one parent's mental health (A_12). She reported experiencing anxiety symptoms, possibly due to post-traumatic stress:

Respondent	Interview Extract
<p>A_12</p> <p>Mother experienced mental health problems following child's life-threatening asthma attack</p>	<p>M: My GP's very good. He gave me some Temazepam because I was getting terrible nightmares, and then I wasn't sleeping, and I wasn't getting any rest. And so I have them, and I've only used a couple, initially and then a bit later. And again, it's knowing that if I did start to use them regularly and be dependent on them, I would know I'd have to go back and see my GP or I would know I'd have to go back and talk to somebody. So, that, in a way for me, that's almost been like a measure of how well I'm coping, because I've only needed them now and again, when I've had a run of nightmares and I just seem to be getting into a cycle of it and I just need to knock it on the head. And I might do two nights with Temazepam and then whatever. But it's knowing that if I was ever to need them or become dependent on them, then I'd probably have to go and have a chat to someone or something. But again, you think, all this is just because I've got a child with asthma. (pause)</p> <p>I: Hmm. Well, 'just' a child with asthma.</p> <p>M: Yes, yes!</p>

Diabetes group

One couple (D_14) felt that the difficulties they had experienced since diagnosis (due to the child's non-compliance), the demands on their time and the degree of attention and commitment had led to a decision for the mother to terminate a pregnancy. The parents had felt unable to cope with the additional demands of a new child. When interviewed, they said that now was the first time, three and a half years since diagnosis, that they had been able to consider seeking help to deal with their own feelings concerning their decision at the time.

Some other parents in this group reported that they or their partner had experienced depression, which they felt was connected at least in part with the diabetes. They had all sought medical treatment: D_3 (father), D_4 (father), D_7 (mother), D_8 (mother), D_11

(father). Others reported other problems with managing their child's behaviour, for which they sought family therapy or parenting support (D_2, D_5, D_14, D_15), or referred their child for psychological support (D_1, D_8, D_11). (An example is shown within an excerpt in Section 7.5.3, relating to respondent D_7).

7.3.2. Impact on Sibling Life

Asthma Group

The only factors raised by parents in the asthmatic group that were unique were about measures taken for the protection or welfare of the asthmatic child that also impacted on the sibling. These generally related to leisure issues; some siblings couldn't visit zoos or go near animals, or go out at all on occasions when their asthmatic sibling was very ill (A_4, A_5, A_6, A_7), and siblings of A_14 took up swimming because it was 'good' for their asthmatic brother. Otherwise, the only further point was that the sibling of A_12 was sent to a local rather than private school in order to be nearby if her brother had a bad asthma attack. She fell behind on schoolwork when her brother was in hospital, leading to some difficult interactions with the teacher, which she found upsetting (A_12).

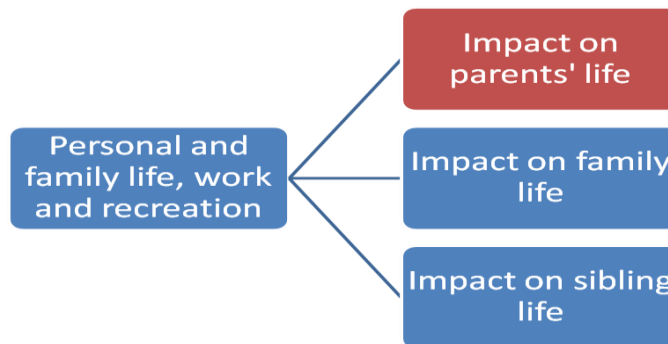
Diabetes Group

Some siblings of diabetic children experienced changes in terms of having more regular mealtimes and / or having a 'healthier' diet, for the benefit of their diabetic sibling. Parents did not report how siblings felt about these changes, although one sibling (D_14) ate more vegetables than his diabetic sister, which parents believed was an attempt to gain attention or to compensate for his sister's non-compliance with appropriate eating.

7.4 SUMMARY AND DISCUSSION OF SIMILARITIES AND DIFFERENCES IN PERSONAL AND FAMILY LIFE, WORK AND RECREATION

The reports of parents in both groups had much in common in relation to their description of the impact on their personal and family lives, work and recreation. Minor differences were noted in relation to the illness-related causes and extent of the impact on areas of personal, but not family life. Other minor differences were noted in relation to the impact on siblings' life.

7.4.1 Impact on parents' personal life - both groups



Whilst parents from both groups reported an impact on the same aspects of their personal lives, with the exception of sleep disturbance and possibly vigilance and monitoring of health state, the parents of diabetic children seem to perceive the degree of the impact to be greater. For the parents of asthmatic children, sleep disturbance and the need to be ‘on the ball’ and aware of changes in their child’s health seemed particularly significant in affecting parents’ personal lives. Possibly the latter was because attacks were sometimes unexpected and life threatening, which demanded extra vigilance. Those more significantly affected in the asthma group tended to have a child with very poor asthma control, and also the child was often very young so could not take responsibility themselves. Also, frequently these parents were single, which could also contribute to a reduced social and working life as their responsibilities were often greater. A preoccupation with monitoring the child sometimes resulted, which affected parents’ mental state and sometimes their ability to focus upon and engage optimally in leisure and employment. One parent experienced significant anxiety following her child’s life-threatening asthma attack.

Although it is a generalisation, there seemed to be a tendency for parents of diabetic children to be more significantly affected by the other areas – i.e. time, effort and features of treatment, feeling the burden of care or weight of responsibility, working life and / or potential working, financial impact, socialising / going out or going away with partner or friends and change of parent’s lifestyle habits. A reason why the parents of asthmatic children seemed to have experienced less of an impact on their personal life is that finding child care (for either leisure or work activities) seemed to have been a little easier for them, possibly because there was no need for the carer to give injections. Furthermore, for most asthmatic children there are periods of relief from attacks, and regular treatment for most of these children tends to be fairly routine and straightforward (except during periods when the child is ill).

In contrast, the children with diabetes needed careful regulation of blood glucose, requiring the balancing of diet, insulin and exercise. Thus babysitters or others who might care for the diabetic child would need a higher level of skills and knowledge. This could partly account for why employment may have been particularly difficult for them. Short breaks in an evening, taken around injection times, were also easier for these parents than trying to go away for a weekend without their child, again possibly due to the complexity of diabetes treatment management. Also, parents of diabetic children seemed usually to experience less enjoyment in their social activities and work because of worry, and feeling the burden of responsibility all the time (rather than primarily at times when the child was ill). This may have contributed to the higher reporting of mental health problems, particularly depression, by parents in this group.

Parents in both groups generally found it easier to have a more active working and / or social life (or consider doing more things socially) when their child was a bit older and more able to take responsibility for themselves. This point may not always be recognised when assessing family support needs. Also, if parents had experienced a fright, for example with a weekend away not going to plan in relation to the child's health care, they expressed feelings of guilt and this often deterred them from trying this again in the immediate future.

Restrictions in a parent's social and working life, if this impacted on the opportunities to develop meaningful friendships and to maintain financial security, may negatively impact on a parents' adjustment. Similarly, not being able to take time for leisure or away from their usual environment may contribute to having little relief from stress.

7.4.2. Impact on parents' personal life - unique to each disease group

Disease-specific issues affecting parents of asthmatic children included the need for extra time to be spent on housework (to reduce possible allergens), and restrictions on going out, particularly when their child was unwell. A parent in this group whose child had experienced a life-threatening asthma attack reported significant anxiety and nightmares, possibly related to post-traumatic stress. Life-threatening illness episodes were not reported in the diabetes group.

One couple from the diabetic group had found the experience of caring for a diabetic child so demanding that they felt unable to continue with a pregnancy. This couple reported significant difficulties in family interactions due to their child's non-compliance, eating problems and poor diabetes control, which may have made their situation more stressful than

could be the case with other couples in their situation. The problems reported by parents in this group in terms of their own psychological health were more commonly depression and parenting difficulties.

7.4.3. Impact on family life - both groups

Parents from both groups reported some difficulties or challenges when preparing for and experiencing family outings or holidays. There was variability in both the impact of the experience itself and response by the parents. In the asthma group, some were restricted in leisure and holiday activities, primarily when the child was unwell (or had recently been unwell), and / or where destinations would have exposed children to triggers (e.g. where animals were present or environmental conditions were not good for the asthma). Other parents seem to have experienced minimal impact, particularly where they did not mind, for example, not having exotic holidays.

Although there was also variability in experience and response in the diabetes group, parents more often reported feeling worry or difficulty during the holiday (e.g. due to unstable blood sugar). Possibly these parents were acutely aware of the long term complications of poor blood glucose control, so may have experienced a higher state of anxiety when control was poor during a holiday. These parents may need further help to predict and manage unexpected experiences when away; an instruction sheet on managing insulin on holiday may not be sufficient. This may help to reduce stress and increase enjoyment and relaxation on holiday. On the positive side, a number of parents expressed that the child's diabetes control improved with experience in subsequent years.

7.4.4 Impact on sibling life - both groups

Parents from both groups reported similar sibling experiences relating to witnessing attacks or hearing distressing information. Some of the siblings in the asthma group witnessed severe attacks, hospital admissions that were life threatening or learned that asthma was life threatening. For these reasons, the sibling response of 'clinging' or being very protective of their asthmatic sibling is understandable, as they may have feared the loss of their sibling. Siblings of diabetic children also witnessed acute illness episodes (such as having a fit), which were distressing for them, and some siblings afterwards became more protective. However, although frightened, they did not express a fear of the sibling's death and parents did not report the 'clinging' behaviour seen in some asthmatic children's siblings. Perhaps

also the siblings were aware that such attacks could be prevented, and how. This might have made them feel less anxious about the episode being repeated.

Siblings from both groups participated in the medical care of the chronically ill child (including recognising and reporting symptoms and assisting with medication or other treatment). Some parents felt that the sibling gained in maturity and caring skills through this level of participation. Sibling involvement in medical care was more commonly reported by parents of diabetic children, possibly because the diabetic treatment is more complex and varied, and takes more time to administer during the day. When the diabetic child is at school, the sibling is often the one who is the available individual (other than the diabetic child) who knows most about the symptoms, diet and medication, so may be more likely to be involved. On the negative side, the sibling relationship was not always supportive.

Some parents reported that they gave less time and attention to siblings (or the siblings perceived this), whilst others did not. Also, some siblings apparently felt resentful about perceived greater attention to or preference for the chronically ill sibling. Parents differed in whether or not they said they treated their children differently. Unsurprisingly, where less time and attention was given or where siblings were treated differently, parents reported that this sometimes led to siblings feeling resentful. The asthmatic children's parents often reported a particular closeness to their asthmatic child (particularly when they were themselves asthmatic, and / or when the child had had life-threatening hospitalisations), and this may have led to siblings' perception of there being a preference for the asthmatic child. Parents perhaps may benefit from becoming aware of this risk, in order to avoid engendering sibling resentment.

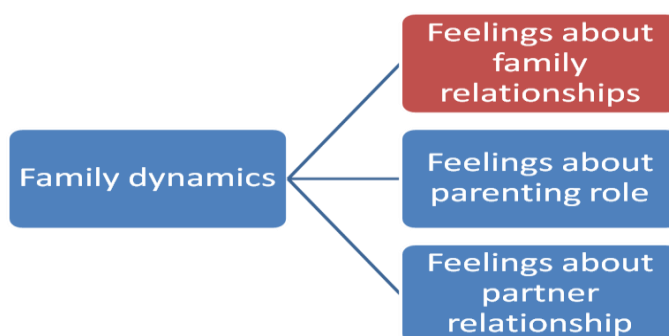
In the diabetic group, sibling perceptions of differences in treatment tended to focus around differences in parents' allocation of sweets and treats. An uncommon strategy was for parents to restrict or deny sweets for all the children in the family; the parents seemed to feel that the family needed to be a 'team' and to empathise with the diabetic child. Other parents said the siblings had just as many sweets as previously, and that the diabetic child was offered alternatives (e.g. a comic). This is an issue that may be useful to discuss with parents and siblings at an early stage following diagnosis, so they can minimise the development of sibling resentment.

7.4.5 Impact on sibling life - unique to each disease group

Some disease-specific differences in sibling experiences were reported which related to leisure (asthma group) or mealtimes / eating (diabetic group). The asthmatic children's siblings had fewer (or in one case more) leisure opportunities (e.g. going to the zoo). Parents did not report that siblings resented this, so it might not have been a very significant issue for them. One teenage sibling smoked despite knowing it was harmful for her brother (as discussed previously). The only difference in the diabetic group was that for some siblings, food and mealtime habits changed. Again, this was not reported by parents as having a negative influence on sibling responses.

7.5 FAMILY DYNAMICS – ISSUES COMMON TO EACH DISEASE GROUP

7.5.1. Feelings about family relationships



As discussed in section 7.1.1, the first of these sub-themes relates to how parents described the functioning and coping, and their experiences of changes in relationships within the extended and 'core' family as a result of the illness. The way the 'core' family functions and the relationships with the extended family may be important for parental adjustment. For example, feelings of being supported within and from outside the immediate family may contribute to family resilience, and similarly, the reverse may be detrimental. Factors common to both illness groups will be discussed together, and similarities and differences will be highlighted. There were a few unique, disease-specific factors that were found that affected family relationships, particularly in relation to how family relationships had changed since diagnosis. Therefore, there will be a short section on family relationships that refers to unique, disease-specific issues. This will be followed by a summary, comparing similarities

and differences across groups in these key areas of family relationships. Details may be found in Appendices 7.7 – 7.8.

‘Core’ family relationships

Asthma Group

Many respondents talked about how they coped as a family, for example by ‘pulling together’ (A_12, A_15), by being positive and accepting (A_5, A_11, A_12, A_14), by ‘getting on with it’ or making the asthma ‘routine’ (A_5, A_10, A_12, A_14), and not letting it run the family’s life (A_12). One couple, parents of a very young child, said they coped by reading a lot about the illness and treatment, and discussing it together (A_16); others tried to ‘play it down’ (A_15), or tried to listen and communicate more, and encourage the child to ‘speak up’ (A_4).

Few parents reported negative experiences within the core family relationships (i.e. other than in the context of a parenting or partner relationship, to be discussed later). One lone parent who had little support from the extended family said she worried about being alone and with little extended family support, and this also make it harder to be patient with her child (A_3). One divorced parent said the family focused on the asthmatic child as most important, but that one core family member ‘didn’t understand’ (A_5). Interestingly, this mother believed that the family’s focus over many years had been on the needs of the asthmatic child, and this may have contributed to the teenage sibling’s behaviour. This lack of support from a core family member is illustrated below:

Respondent	Interview Extract
<p>A_4</p> <p>Teenage sibling smokes, ‘doesn’t understand’</p>	<p>M: I’ve got a teenage daughter that keeps smoking, and she doesn’t understand. And I keep trying to tell her, but it goes in one ear and out the other. She just says, ‘Oh, you’re just protective’. They don’t realise the implications of smoking.</p> <p>I: Does that cause any conflict in your household?</p> <p>M: Yes.</p> <p>I: ..That your teenager smokes?</p>

	<p>M: Yeah. Yes, I say, ‘You can smoke outside the house as much as you like, but you still smell a bit when you come in’. So the argument is, ‘I don’t smoke in the house. I don’t smoke near him’. ‘Yes, but you still smell of it when you come in’.</p> <p>I: So you haven’t quite sorted that one out yet.</p> <p>M: No. (Laughs).</p>
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Diabetes Group

Parents in the diabetes group also reported how the family ‘pulled together’ and were a ‘team’ (D_1, D_3, D_8, D_11, D_12), or tried to be a ‘community’ at mealtimes (D_14). A number of parents said ‘counting one’s blessings’, thinking positively about the family’s ability to cope, and / or not blaming the diabetes for family problems was helpful in their adjustment (D_1, D_3, D_6, D_8, D_11). Being accepting of the diabetes, or making it ‘routine’ was helpful for some families (D_4 (father), D_5 (father), D_8), as was reading about the illness and treatment, and sharing this (D_12). Living more healthily as a family (D_5), and listening and communicating with each other (D_1) were also reported as positive for the family.

On the negative side, two parents reported that the family’s positive or negative feelings were affected by the blood glucose levels of the child (D_7, D_11). Some parents expressed worry for the family due to them being alone (as a lone parent) (D_7, D_15), about the undue focus on the child with diabetes, leading to family arguments (D_4, D_7) or tension and communication problems due to competing needs within the family (D_14, D_15). Sometimes parents reported that family difficulties occurred when one or more core family members did ‘not understand’ (D_6, D_15, D_16).

In the following excerpt, the parent (D_3) explains that the focus on the ill child to the detriment of other family’s needs was recognised as not being adaptive, and reported that this changed. Additionally, having a common focus for something positive (fundraising) was helpful in promoting family adaptation and cohesion:

Respondent	Interview Extract
<p>D_3</p> <p>Family recognised too much focus on ill child, neglecting other family members' needs.</p> <p>'Giving something back' helped family cohesion and adjustment.</p>	<p>M: I have a son too, that's older than [child's name], and it was a family concern. And I would like to stress that, that it is a family concern. Because suddenly, your life is different, and I think to a certain extent, you are all confronted with a new experience that you can't pretend doesn't exist.....We didn't appreciate at first that [child's name] had suddenly become the pivot around which everything followed, and we didn't always recognise the feelings and needs of all the family.</p> <p><i>The parent explained that family needs were now better recognised, and that 'giving something back' as a family helped them all to cope and work together in a positive way:</i></p> <p>M: We did loads of fundraising last year, because I think that channelled our energies for the Oxford Group [Young Diabetics Group]. And again you want to show your thanks almost for what they've given you, by giving something back. And I think that did us all good as a family.</p> <p>I: Everyone got involved with that.</p> <p>M: Yeah. Husband, son, everybody, children, everyone.</p>

Extended family relationships

Asthma Group

Relationships with the extended family were commonly viewed positively, for example, they were described as 'pulling together' with the 'core' family (A_3, A_13, A_15), cooperating in general functioning (A_3), showing empathy and understanding, and being protective of the child (A_2, A_6, A_11). Grandparents often became more involved (A_2, A_6, A_7, A_13, A_15).

Whilst some respondents said that some or all extended family members were supportive at all times, in practical and/or psychological ways (A_2, A_6, A_7, A_11, A_15), it was also reported that some or all of their relatives were only supportive during a crisis (A_2, A_3).

However, it seemed that the lack of understanding of the parents' experiences by some members of the extended family was stressful for the parents (A_2, A_8), as well as a lack of

capability of dealing with asthma symptoms (A_2, A_8). Most of the above points are illustrated in the following excerpt:

Respondent	Interview Extract
<p>A_2 Pre-school boy</p> <p>Positive and negative feelings about family relationships</p>	<p>I: So what would you say were the times you felt most positive about your family's relationships, since [child's name] has been diagnosed, and why do you think that was?</p> <p>M: Whenever I've needed them to be there, they've been there, and I know they always will be. Everyone, I know, it's like my ex, it's his only son, his only child, and he absolutely dotes on him. Me Mum, it's her only grandson. She's got granddaughters, but she absolutely dotes on him. They'll do whatever they can for him, I know. My stepdaughter as well, she worries about him when he gets wheezy and that; my husband has come up to the hospital before, even if it's just to take me out of the room for ten minutes, give me a coffee, you know, I'll go back in there and sit in the room. If I get ten minutes, out of the room for ten minutes, get myself some fresh air, in a way, it does bring you closer. But in a way it can also cause more arguments (laughs), because as a parent, you do get ratty. When you're under stress, you can't help it. You do get stressed. And you shout, you lash out because you can't lash out at the asthma. That is the worst thing. It's something, as I say, if a person upsets you, hurts you, you can lash out at them. But with asthma, you can't. It's something that's not there. You can't see it with your naked eye. And you can't, so there's times where you do just lash out. Also, as I said, where you've got people that know about it, they understand it. And they're there because they understand the pressure, the stress that you're under. And you can just sit there and just (claps hands). At the minute, touch wood, he's been fine. So, me stress level's coming down. But again, as soon as a cold comes, my stress level will go up. And as I say, my family are always there for me. I know if [child's name's] admitted into hospital, I know I can ring me Mum, she'll get her partner, and even if she has to drive up just for a couple of hours with her partner, she'll drive up there. She'll do it just to give me a couple of hours' break. And I know that he will do that with my Mum. Anybody else, no he won't.</p> <p>.....I mean sometimes it can cause arguments, asthma, between parents and family members that don't understand it, that haven't been there. And it can also help bonds with family members that have been there with you through it, because they know what you're going through. So, I don't think there's ever a positive about asthma, there's always negatives, but in a way, when another family member knows what you're going through, it can, you can get a good bond with someone because they know what stress you're under. You know, I suppose that's the only good thing.</p> <p>....</p> <p>I: So, would you say that your family's changed any of their behaviour as a result of your child having asthma?.....</p> <p>M: Well whenever we go to stay there, my Mom cleans the house from top to bottom (laughs). Flowers are out in the living room, and anything</p>

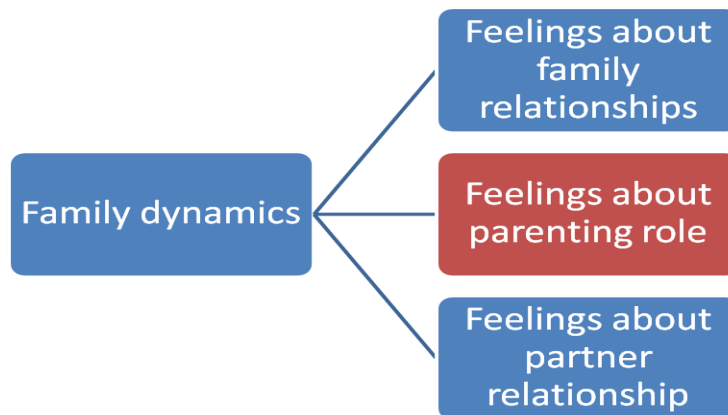
	<p>that she can do to make sure he's [child's name's] OK. One of my brothers actually made a comment that I wrapped my son in cotton wool. And I had a go back at him, because he has twin daughters and they're fine, they've got no problems. Normal 7, 8 year olds. And then 2 days later, he [asthmatic child] ended up in hospital with his asthma. That shut my brother up. It actually shut him up. He actually realised, well he'd never seen him get ill. I think it actually surprised him... I think he just thought...you know, he'd probably seen other people with asthma inhalers – puff, puff, fine – off they go. He's not seen a child having to deal with it. And I think it did change his perspective on it. So, I think he can understand why I was paranoid now. I said, 'If you can imagine your daughters, supposing one of them had it', I said, 'it's worse if one child can run around and do everything, and the other one can't'. I said, 'they'd run around for 5 minutes and then they'd get out of breath'. I said, 'that's what you've got to think about'. I think it has changed his attitude towards it. And I think it did change my Mom's, 'cause she actually stopped smoking. She actually quit smoking, I think 2 years after he was born.</p>
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Diabetes group

Similar points were made by respondents about the support provided by extended family members (D_2, D_11, D_16), although some were only supportive during a crisis (D_7). Increased involvement of grandparents was also mentioned (D_2, D_15). However, negative aspects were more commonly mentioned, particularly the lack of capability of some or all relatives to deal with diabetes (D_1, D_7, D_9, D_11, D_15, D_16), which was sometimes associated with a lack of understanding of diabetes and/or of the nature of the experiences of the 'core' family (D_1, D_7, D_9, D_15). On the other side of the relationship, one couple said their child 'manipulated' the grandmother (D_14). The lack of understanding of relatives about diabetes, contributing to lack of support is illustrated in the following excerpt:

Respondent	Interview Extract
<p>D_1 School aged boy Extended family not understanding</p>	<p>M: Well, my aunt will phone up at Christmas, and she's about 80 now and she'll go, 'And how's the boy – is he better yet?' (laughs) 'Still diabetic? Oh dear, that's a shame isn't it?' (laughs)</p> <p>I: (laughs) So you've found, like grandparents and other relatives don't really...</p> <p>M: The old ones don't get it at all. They just don't get it. They really just... or they'll go, 'I've bought you an Easter egg, just a small one, 'cause I know you don't eat chocolate' (laughs). Little things, but they mean it with the best will in the world. It's not as though it's done, they don't go, 'Oh let's say something stupid and see what she does'. (laughs) It's just life, isn't it?</p>

7.5.2 Feelings about parenting role



In Section 7.1.1, it was explained that many respondents talked about their experiences within their parenting role. Whilst these parents in some ways face similar challenges as parents without a chronically ill child such as supporting, educating, protecting and providing discipline, some variations on the same issues are evident in the different disease groups.

Parents in both groups talked about the following aspects of their parenting role. (For details, see Appendices 7.9 and 7.10). Some of these related to parents' reflections on what it felt like to be a parent (both positive and negative), and some related to their parenting actions, including accounts of why they parented in a particular way, and the challenges or difficulties experienced:

- *Feelings about parenting in general (positive and negative aspects)*
- *Supportive / encouraging behaviours towards child*
- *Treating the child as 'special' (including being very protective, 'spoiling', giving more attention, hesitancy about providing discipline, treating child differently from siblings)*
- *Treating the child as 'normal' (including trying not to overprotect, not 'spoiling', ability to provide consistent discipline, treating children equally to siblings)*

Feelings about parenting in general – Asthma Group

Four parents (A_2, A_5, A_7, A_9) talked about how sometimes they felt quite ‘alone’ as a parent, feeling it was more difficult for them than for parents without an asthmatic child or that others (including doctors) didn’t fully appreciate what they faced. The following example is illustrative:

Respondent	Interview Extract
A_9 School aged boy Finding it hard to parent; others not appreciating difficulties	M: I always feel I’m being put on the spot. I’d like a bit more sort of, support in a way, rather than...[when meeting with doctors] it is very, quite cold and detached and clinical. But I mean they’re lovely with [child’s name], don’t get me wrong, but I feel that perhaps they don’t realise it’s quite hard to be responsible for somebody’s care, when you’re not a professional. You know, and it’s the only instance of asthma I deal with. I: Exactly. M: I’ve found it is quite hard.

Positive feelings about being a parent were also reported, for example when the child overcame difficulties, did something independently or coped well (A_4, A_8).

Feelings about parenting in general – Diabetes Group

Parents in this group also reported a sense of feeling ‘alone’ as a parent, or feeling it was harder for them than for other parents (D_2, D_4, D_11, D_15). A couple of parents talked about difficulties in making decisions about what to allow the child to eat, bearing in mind the need to balance any upset for the child against the negative consequences of poor blood glucose control (D_8, D_11).

Similarly to parents in the asthma group, feelings of pleasure and pride were expressed about occasions when the child made an achievement despite difficulties, or coped well (D_1, D_16), as in the following example:

Respondent	Interview Extract
<p>D_16</p> <p>Adolescent boy</p> <p>Parent is proud of child's acceptance of diabetes, even since diagnosis at age 12.</p>	<p>M: I mean, he's been brilliant about it from the moment... I mean he's never complained about it from the moment he was diagnosed. I'm the one that's done all the crying and all the moaning, you know, and he's the one that's been, 'Well, it could be worse, you know.' And I think, 'Oh, from a twelve year old'.</p>

Supportive / encouraging behaviours towards child – Asthma Group

Parents reported ways in which they provided support, education or encouragement to the child (A_5, A_6, A_13), about things such as school work, understanding their treatment in an age appropriate way, or reassurance when distressing experiences occurred.

Most of these issues might have been expressed by other parents of children of a similar age and stage of development, but in the case of children with a chronic illness, there can be an added dimension. For example, very young children might fear separation, and parents would act to help the child feel more secure. However, when children have frequent hospital visits or admissions at a young age, they may need additional parental support or interventions, as in the example of A_13:

Respondent	Interview Extract
<p>A_13</p> <p>Pre-school boy</p> <p>Experience of frequent hospitalisation / hospital visits – need for providing extra reassurance</p>	<p>M: Yes, we always stay with him don't we? There's always one of us is with him. He's getting more anxious. When we got in the car to come [to clinic] today, we told him we were coming and he was 'No, stay home. No, stay home'.</p> <p>F: Previously, he like....</p> <p>M: No, he didn't know where he was, did he?</p> <p>I: He doesn't like coming to hospital as much now.</p> <p>M: No, and it's a bit more persuasion to let the doctors listen to him, isn't it?</p> <p>F: Yeah.</p>

	<p>M: Whereas, he would have just sat and it wouldn't have bothered, him, he's now very clingy round your neck.</p> <p>I: And how do you usually respond when he's upset?</p> <p>M: I suppose we just carry on. We're here to see the doctors, so just...</p> <p>F: Just carry on quite quickly.</p> <p>M: We always make sure he can trust us not to leave him and disappear, or he knows that we'll always stay with him.</p> <p>I: So you just talk to him and reassure him.</p> <p>M: Yes, yes. Diversion sometimes, we get him to look at cars.</p> <p>I: And that usually works.</p> <p>M: Yeah, yeah.</p>
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Supportive / encouraging behaviours towards child – Diabetes Group

Some parents described how they showed empathy towards the child, to indicate that they had some appreciation of the challenges of the illness. For example, parents injected themselves (D_3, D_12) or avoided eating sweets in front of the child (D_8).

Parents also described how they encouraged their child, for example about appropriate eating, being open with others, talking about their problems or trying hard at school work (D_1, D_4, D_10, D_12); efforts to explain reasons for treatment and risks in an age appropriate way, or encouraging them to be more responsible were also reported by parents (D_5, D_7, D_8, D_11, D_15). However, not all parents felt they had achieved success in these efforts.

Another area of providing support was in the area of being an advocate for their child, for example with regard to bullying or standing up for the child to have a normal school experience with good diabetes control at school (D_1, D_2, D_8). The following is an example the parent acting as advocate:

Respondent	Interview Extract
<p>D_8</p> <p>Adolescent girl</p> <p>Parent being an advocate for the child</p>	<p>M: Her circle of friends is 5 or 6 of them in a group and they took it upon themselves to bully [child's name]. And school said there wasn't anything going on and all the rest of it. So we were doing it like a process of elimination – you know, if I could get her to school, they would accommodate whatever. If she didn't want to do PE, they would accommodate her on a temporary basis, 'cause I thought it was PE. But it all came to a head last week that she's being bullied by her friends.</p> <p>F: I think the point that makes us slightly different from a parents' perspective, is the fact there's a concern that if she's eating and not injecting, there's going to be a knock on effect on the diabetes. Which there has been.</p> <p>M: It's not the first time.</p> <p>F: It just adds that extra complication into what is already a complicated thing for a parent to deal with. I don't think it makes it tremendously worse, but it gives you an extra concern, you know? But, by the same token, it also gives you extra leverage with the school. So.. if you're prepared to use it. You know, because we had a meeting with the school last week and I just laid it on the line and said, 'Look, my priority is [child's name] - obviously, as a parent. But my priority is even more enhanced because it's affecting her diabetes'. I said, 'And I'm demanding that you do something about it'. So, you know, it does give you that extra little bit of clout maybe, I don't know.</p>

Treating the child as 'special' – Asthma Group

A common belief expressed by parents was that they protected their child too much (A_6, A_7, A_8, A_11, A_12, A_14), for example due to worry about exposure to asthma-related risks or because they did not trust others to care. Many of these parents also commented that although they felt compelled to be overly protective, they were unhappy about this over-protection because they believed it limited their child's development opportunities.

Other aspects of treating their child as 'special' included what parents described as 'spoiling', for example giving them extra treats to compensate for their illness or allowing their child to have their own way (A_5, A_7, A_15). Sometimes this was complicated by the parent being unsure whether the child's behaviour was manipulative, or whether there was a genuine illness-related reason for oppositional or other types of behaviour, as shown in the following example, where the parent had originally 'spoiled' the child, but was now trying not to do so.

She had now recognised that the difficult behaviour was not necessarily caused by the asthma (partly because the asthma severity had decreased over the years), but previously she had been uncertain about whether or not the behaviour (school refusal) was related to asthma. This made disciplining difficult:

Respondent	Interview Extract
<p>A_15</p> <p>Adolescent boy</p> <p>Parent beliefs about 'spoiling' and providing discipline – earlier uncertain attribution</p>	<p>I: Do you think that [child's name's] asthma affects the way you relate to him at all?</p> <p>M: Not any more. It did for a long time. He got away with things he wouldn't normally have got away with. And he did milk it a bit. He milked it a bit, didn't he? Because he knew that he could, I mean there were times he was off at school, where he didn't need to be off of school.</p> <p>I: So he'd say, 'I'm wheezy Mom', and you'd keep him off.</p> <p>M: Yeah. Yeah. And I tended to more than coddle him, quite a bit. And I'm just a big softie by nature anyway, which doesn't help. But yeah, it definitely affected it. He was quite spoiled. He was quite spoiled. He's not so bad now, but he was horribly spoilt.</p> <p>I: So what made that change, do you think, because you were saying he's not quite like that now, you don't feel like that now.</p> <p>M: Oh, he's a teenager (laughs). I don't have much influence now! Yeah, it's the teens. And also, as he got better, you know, and he'd sort of (makes heavy breathing sounds), and say, 'I'm so sick Mummy', I'd say, 'You're not...are you buggering? Door's that way'.</p> <p>I: So he didn't stop trying it on, really?</p> <p>M: (shakes head)</p> <p>I: He still tries it on?</p> <p>M: Yeah, he still tries it on.</p>

The grandmother of this child (who lived in the household) however felt that she was able to be firm, so the mother described the child relationship situation as being a 'good cop (herself) / bad cop (grandmother)'. This inconsistency of discipline may have made it more difficult to manage the child's behaviour, a possible additional stressor in the household.

Treating the child as ‘special’ – Diabetes Group

Parents’ belief that they were over-protective of their diabetic child was very commonly expressed (D_1, D_3, D_5, D_8, D_9, D_10, D_11, D_12, D_13, D_15, D_16). This was often described by parents of older children who were approaching their teens or who were already teenagers. Whilst recognising these young people needed to have more independence, there was often a worry about risks, as in the following example:

Respondent	Interview Extract
<p>D_9 Adolescent girl</p> <p>Feeling protective and worried about ‘letting go’</p>	<p>M: I actually feel now that she’s growing up, and it’s taken out of my hands, and it has to be because [child’s name’s] going to be independent, but I feel that she wouldn’t do as good a job as me. And that’s what I worry, ‘What if? What if?’ You know, ‘What if she goes out one night to Oxford and she’s coming back on her own on the bus and I think all sorts of things. I’m sure all mothers think like that anyway, but when she’s got diabetes, I’m thinking, ‘what if she feels low?’ And I’m saying to her, ‘Have you got a snack?’ Oh, she’d get touchy. ‘Have you got Dextrose?’ ‘Oh, tsk, I don’t like them!’ And you know you feel, it’s that sort of thing. And so I feel frustrated and I feel as though, you know, perhaps I can’t quite let go, but I don’t want to now, so now I feel, I suppose like I did at the beginning, when I was worried and anxious about everything and I was with her every day.</p>

Whilst, as this mother expresses, concerns about child safety are often felt by parents of unaffected children as their child becomes more independent, anxiety may be accentuated by additional worries about the diabetic child’s health.

The above example also illustrates another concern of parents of teenage children, which was the need to ‘nag’ them to get them to look after their own health (e.g. do blood tests) (D_7, D_8, D_9, D_11, D_13). Both parents and teenagers found this type of interaction stressful – the parent disliked nagging, and the teenager responded negatively to being nagged. Some parents felt that this negativity marred their relationship with the child. Again, although this type of interaction may not be unusual between parents and their teenage children, it may be more common with diabetic teenagers because of the parents’ concern about the risk of the teenager not adhering to their treatment. Therefore, the consequences of the diabetic teenager not looking after their health adds a different dimension to essentially normal experiences of parents of unaffected teenagers.

Similarly to the asthma group, disciplining of ‘misbehaving’ children was sometimes difficult for parents because of uncertainty about the cause of their child’s behaviour. They treated the child as ‘special’ by sometimes giving the child the benefit of the doubt by not disciplining them; they accepted that the child’s difficult behaviour could be due to abnormal blood glucose levels or anger about the diabetes (D_5, D_14). Others thought it could be due to the onset of puberty, which can lead to disruption of the blood glucose control of even well controlled diabetics (D_3, D_8, D_13). Some parents also let their child choose what they would eat (which was not always appropriate) because of worries about the child developing hypoglycaemia (D_2, D_4, D_14). Particularly where the respondent’s spouse / partner did not agree with this degree of leniency, this sometimes led to difficult and stressful family interactions (D_4, D_8); these parents were among those who had also reported arguments about treatment issues such as whether or not to give the child a snack at night (D_3, D_4, D_5, D_6, D_8, D_13). Interestingly, some parents said that there was less conflict between the parents and child after the child had started on the new ‘basal bolus’ insulin regime, where the child injected insulin according to what they ate (rather than injecting a set amount in advance).

Treating the child as ‘normal’ – Asthma Group

Some parents said they consciously tried not to overprotect their child (A_2, A_3, A_4, A_10). It should be noted that A_10 was the one parent whose child was mildly affected by asthma, and A_3 had a teenage daughter who had been generally well for years (apart from one serious, life-threatening attack and now that she was on the correct medication, her asthma was well controlled). The child of A_2 was only 4 years old, and she therefore would have been exerting a high degree of control over the child’s activities anyway. Therefore, parents in these situations may find it easier to protect their child at a developmentally appropriate level.

Respondent A_4, whose child had less well controlled asthma, still tried to encourage her child to do things independently and carry out normal age-appropriate activities. The child had experienced years of restrictions, and the parent felt it was important that the child did not continue to experience this, but have experiences as close as possible to that of a ‘normal’ teenager, as shown in the following excerpt:

Respondent	Interview Extract
<p>A_4</p> <p>Adolescent girl</p> <p>Wanting not to overprotect the child, but let her do 'normal' things</p>	<p>M: I mean, we end up, if she's doing a bit of babysitting, we end up with our fingers crossed that she's going to be well enough to do it. You know, there's a lot of 'a wing and a prayer'. We arrange things and we just really hope. And she's got school plays coming up, three nights, and we know that there's every chance that she'll be poorly, but she'll still go on. She'll push herself and we're just hoping, we just hope that she can do it. So you end up on a bit of a knife edge sometimes, thinking, 'I really hope she can do what she wants to do'..... I'm of the philosophy, we'll try it. I could wrap her in cotton wool but it's only going to make her cross and frustrated and she'd go and do it anyway.</p>

Treating the child as 'normal' – Diabetes Group

Parents of diabetic children sometimes described trying to treat their child as 'normal' (D_1, D_6, D_8, D_13), for example treating children (within reason) as they would if they did not have diabetes. Some of these parents said that they tried hard not to be overprotective, such as the parents of D_13, who encouraged their child to be more independent, go out and play or go swimming without the parents. However, the child preferred to stay at home or not go out alone. They expressed concern that this could be because they had been too overprotective:

Respondent	Interview Extract
<p>D_13</p> <p>Adolescent girl</p> <p>Wanting child to have 'normal' experiences, not overprotecting</p>	<p>F: We say, 'Why don't you go out to play?' 'No, don't want to.'</p> <p>M: I found it, you know, she sort of went like it [diabetes symptoms] before she was diagnosed, wasn't she, and I think it scared her.</p> <p>F: See, now whether that's us being too overprotective with her again, we don't know.</p> <p>M: I've tried for her to go out, but she'd rather sit in or wait until we go swimming or...</p> <p>F: It's the old story, you can take a horse to water but you can't make it drink.</p> <p>M: (Laughs).</p>

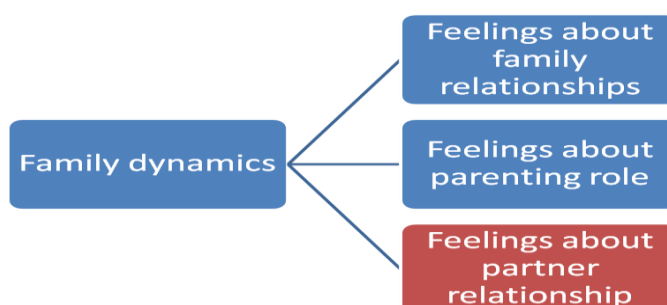
	<p>I: So, how do you feel about that, the fact that she seems to be more of a home body now?</p> <p>M: Well, I think it's sad. I think it's very sad that, you know, in a way, her childhood sort of seems to have been...lost.</p>
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Other ways in which parents tried to treat their child as 'normal' was to allow sweets in a controlled way (D_4, D_5, D_8). For example, the father of D_8 felt it was important for the child's psychological health for them to be allowed 'small transgressions' of food indulgences like other children (even though it might not be ideal for her physical health):

Respondent	Interview Extract
<p>D_8</p> <p>Allow 'transgressions' of sweets like other children, for psychological health</p>	<p>F: Sometimes I think you have to sort of balance how much upset it's [applying limitations on sweets] going to cause against how much damage is likely to be caused by allowing one slip to go. Do you know what I mean? And your priority (looking at wife) is the medical side, isn't it, and I try to balance the psychological side against the medical side – which isn't easy, 'cause how do you know what someone else is actually thinking? Plus, children manipulate don't they? I mean there's no two ways about that. ...And the other point is, I mean I'm really conscious, you know, because I mean most blokes are like kids anyway, but if you're not allowed to do something, you want to do it all the more, don't you? So trying to allow it within reason, is the balance yet again. And that's what this all seems to be about, really, is about balance.</p>

Other parents described how they tried to treat their children equally, by restricting sweets for all children in the family (D_12) or when allowing sweets for siblings, giving the diabetic child an alternative treat (D_1, D_6), or requiring all children in the family to do the same chores (D_1).

7.5.3. Feelings about Partner Relationship



In the interviews, parents were not asked specifically to disclose their feelings about the impact of the child's illness on partner relationships; they were asked a general question about family relationships. This may be a reason why some parents did not discuss this topic. Other reasons were that some respondents were single parents without a partner, others may not have considered that their child's illness affected their relationship with their partner, and / or parents may have considered that this topic was too personal to discuss in an interview.

It is acknowledged that in most cases, what was gained was the mother's perspective on the impact of the child's illness on the relationship with her partner. It is possible that the fathers may have viewed this differently. However, the father's perspective was gained in those cases where a couple were interviewed together (i.e. 2 cases in the asthma group and 6 cases in the diabetes group). The following sections will separately consider the data where the mother was the sole respondent, and where both parents were interviewed, in order to better highlight such possible differences.

A further factor affecting the structure of this discussion is that most respondents discussed this aspect of family relationships in the context of describing the extent to which they and their partner shared the child's care management and other family responsibilities. This factor may be particularly important for partner relationships where there is a child with a chronic illness; the impression was gained during interviews that where parents felt they were able to share the caring responsibilities, giving and receiving both practical and emotional support, they were both able to appreciate the stressors associated with such responsibilities. This may be a protective factor for parental adjustment. For this reason, the following sections will separately consider cases where the mother undertook all caring responsibilities, and where caring was partially or completely shared. Further details are provided in Appendices 7.11 and 7.12.

Mother is respondent: Asthma Group

Separated or divorced mothers (Asthma Group)

Four mothers in the asthma group were separated or divorced from the father of their child, and there was no contact or involvement with him (A_3, A_4, A_6, A_15). The penultimate respondent had since remarried, but the new partner was not involved in the child's asthma care. Except in the case of A_4, where the father left his partner when the child was a young

infant, it is not known whether the mother believed that the difficulties in the partner relationship had been affected by the child's asthma.

Two further respondents were separated or divorced from the child's father, but there was some contact or involvement (A_2, A_5). In both of these cases, the mothers said they felt that their child having asthma contributed to the break-up of the relationship. In the case of A_2, the mother felt that a lack of sharing of the child's care, in conjunction with financial worries, had led to the break-up, although more recently the child's father had been more supportive, as indicated in the following excerpt:

Respondent	Interview Extract
<p>A_2</p> <p>Lack of sharing of caring responsibilities and financial worries contributed to break-up</p>	<p>I: So, since [child's name] was diagnosed, what would you say were the times when you felt perhaps least positive about relationships within your family, and why do you think that was so?</p> <p>M: I think the only negative was in like at first, usually towards my son's father, because he tended to let it all fall on me at the time. And it all came down. It changed when we split, because he's so much better with him and with asthma and everything, but at the time it all came down to me. It'd be like, if he was admitted say three nights in the hospital, it would be me doing the majority of nights. He might do one. But I wouldn't leave there until 10, 11 o'clock in the morning. I'd be back there at 4 o'clock, 5 o'clock, and the rest of the time I'd be there. My ex would leave, and I'd be there all by myself. And it just got...it put a lot of stress on me and my ex, and stress, to do with it. Everything seemed to come down to me.....</p> <p>I: You felt it was an unequal kind of partnership?</p> <p>M: Yeah. Yeah, the sharing. When I'd come home from hospital with him, my ex...unfortunately companies still do not recognise asthma as a disease. It's life threatening. They don't recognise it as something like that. And I have enough hassles to get time off my work with [employer's name], because they are total and utter 'beeps' with things like this, because they do not realise it and they only allow you, which I think is wrong; is you can take, what they deem parental leave. But if you take parental leave, you have to pay the time back to the company. But I'd take some parental leave for five days, I mean I'd been the one who spent the majority of time up at the hospital dealing with it and all the rest of it, so I'd taken the leave off. 'Cause I wouldn't be able to go to work, I'd have been too worried. 'Cause I'd be spending all the time at work worrying about it. And my ex would then take time off work as well. And I'm thinking, 'It doesn't need two of us.' You know, and that put a lot of stress on me as well with things.</p> <p>I: Because it had financial implications, I suppose.</p>

	<p>M: Yes. It did. It did, which put more stress on things, which probably made us split in the end. But I mean, he'd go and take, like 2 weeks parental leave off. And I'm thinking, 'It doesn't need both of us. He'd be at work during the night anyway. So, what's the difference? He'd be asleep and that, and it was just a lot of stress on us as well. I think you find if you've got a couple that do take it, even responsibility, it works out so much better for the child as well.</p>
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The other respondent (A_5) felt that contributing factors to her marriage break-up were that her son slept in her bed until the age of 9 years (so there was no room for her husband), and she believed she had made the child the focus of her life, possibly neglecting the relationship with her partner. She still had contact with her ex-husband, who sometimes had the child to stay overnight, but she did not feel he was competent in the asthma care and this experience was stressful.

Mothers with a partner living in the household – partner involved in caretaking (Asthma Group)

In the cases of the other mothers, the partner lived in the household. In a few cases (to be discussed in the next section), the mother reported that the father had no involvement in caretaking responsibilities. However, in the majority of instances, the father was involved in some caretaking responsibilities of children in the family, although not necessarily for asthma care (A_2, A_7, A_9, A_10, A_11, A_12, A_14, A_16).

Four mothers reported that family caretaking responsibilities were divided between them and their partner, with the mother exclusively managing the medical care of the chronically ill child (A_9, A_10, A_12, A_14), the father occasionally doing this (A_2, A_11), or sharing such care equally (A_7, A_16). The latter respondents felt that the equal sharing promoted their mutual support.

In some cases, this division of labour seems to have been negotiated, and at other times it was apparently assumed that the mother would undertake this responsibility. Where this 'division of labour' was negotiated and agreed the mother felt this took account of each parent's strengths and weaknesses, and was better for her family's functioning, as illustrated by the following excerpt:

Respondent	Interview Extract
<p data-bbox="316 365 384 394">A_12</p> <p data-bbox="316 566 496 696">'Division of labour' in caretaking responsibilities</p>	<p data-bbox="579 331 1406 528">M: And last year...he was in hospital so much, I was exhausted. All year I was tired, because I would catch up from an event and he'd be back in. And people have suggested, well how about sharing the asthma thing between you and your husband? That's a good idea, in principle. But it wouldn't work on lots of levels. One is that I'd be sitting at home worrying anyway, or whatever.</p> <p data-bbox="579 533 1406 864">My husband can do everything, mop up sick, diarrhoea, whatever, but he just can't deal with the asthma...I'd rather... you know, the way that we manage it works for us because I do [asthmatic child's name] and his asthma, and then [husband's name] does [sibling's name]....And he can get her to school. He can make sure she does her homework. He can make sure she's got clean clothes, so she's got somebody who's not snappy or tired or have a mind on something else. And that's how it works for us. It is a division of labour, but not necessarily sort of '[husband's name] does one night at hospital, I do another.'</p> <p data-bbox="579 902 1406 1032"><i>However, this mother did not believe that her husband fully understood the strain of caring for a very ill child, in this case after a life-threatening episode for the child. This is shown in the following excerpt:</i></p> <p data-bbox="579 1070 1406 1267">But I think, as a family, what certainly for me, and probably 'cause a lot of this has fallen on me as the mother, I have to talk things through. I have to deal with things by talking about it. My husband's the complete opposite, which can drive me demented. So, you know, even if I just rabbit and he doesn't really listen, I don't care. If I can just almost get it out, I find that helps me a lot....</p> <p data-bbox="579 1305 1406 1906">When you've been that tired, or you've been that absorbed in something, both immediately afterwards [after hospital admission] and afterwards when you supposedly are rested, or whatever...and I think it is sort of a woman thing, possibly. Things like, I mean I don't necessarily want sex for instance, partly because I'm so tired. You know, OK, immediately after the event, that's understandable. You're just knackered. But even later... and I was trying to say to [husband's name], it's actually got nothing to do with you. It's nothing to do with you. It's I am so mentally and physically drained and my ...I sort of still do think about that but it's gone off the radar. It's just not something I want to do or think about or... and that's hard, I think. I think it's harder for a bloke, because I think they're made differently. They sort of see, they respond and they want to conquer, whereas I think sex for women is much more about other things, sort of factored in. And I think that's hard. So, it's trying to say, 'Well sorry love, you're just going to have to wait. And I don't know how long it is'. But you need a strong relationship to be able to sort of, you know, cope with that.</p>

Mothers with a partner living in the household – partner not involved in caretaking (Asthma Group)

Two mothers expressed that they felt it was their particular responsibility as a mother to manage the child’s asthma, and their husband was not involved in caretaking responsibilities in the home. In one case (A_1), this was partly because the husband worked away from home, and in another (A_14), the husband worked long hours and travelled long distances to work. In the case of A_14, the mother felt she was the one who should get up during the night when the child was unwell and ensure that there was enough medication for the asthmatic children in the family. This exclusive responsibility however led this mother to sometimes feel overtired, contributing to a perception that that the husband was not ‘in tune’ with the challenges of the child’s care:

Respondent	Interview Extract
<p>A_14</p> <p>Mother has exclusive responsibility for asthma care - overtiredness can make her feel husband not ‘in tune’</p>	<p>I: Oh dear, very difficult, isn’t it [having to get up during the night, and losing sleep]?</p> <p>M: It was, and especially for me husband. I mean, in some ways, I see it as that’s the mother’s role. You know, you just get on with it, don’t you? And you go without sleep. But me husband travels quite a distance. He can do, like, 200, 300 miles a day, travelling. So he can’t go without sleep, and he’s developed this inner deafness, where he doesn’t hear them [asthmatic children coughing] in the night, and he hasn’t done that for a long time. . . . We’ve gone through it with all the others. This is just our family pattern. Everyone must go through this. You know, we pull together and get on with it.</p> <p>I: So, you’re saying, you pull together, and that in a way, helps your family to empathise with each other, maybe is what you’re saying?</p> <p>M: It does. I’m talking about the immediate family, because the extended family haven’t really played any part in it. But I think, at the beginning, when you first get diagnosed, although you suspect a diagnosis, you pull together because you think, ‘Well, we’ve coped with it’, you know, with the other two kids. We’ll cope again. I have to work. He has to work. We’ll just have to work it between us. So you’re on a positive. But as time goes on, and you get more and more tired, and it affects the other children, and they’re getting ratty, and you’re getting ratty with them, and then you could punch your husband sometimes, because he’s not in tune, or you think he’s not in tune. And that’s as time goes on, when it causes problems.</p>

Both mother and father are respondents: Asthma Group

As mentioned earlier, there were only two cases in the asthma group where the father was one of the respondents (A_8, A_13). In the case of A_8, the couple shared the caretaking responsibilities, including for the asthma care, and were fully confident in asthma care. On the other hand, in the case of A_13, the mother (who was not working) undertook most of the care of the two children, but the father assisted in all aspects of care (including asthma care under his wife's advice). It should be recalled that there were other cases (where the mother was the sole respondent), where full sharing of caretaking responsibilities was reported.

There may be more positive than negative implications for the partner relationship when both mother and father have equal responsibility for the child's asthma care. This seemed to be the case in the case of A_8, as shown in the following excerpt:

Respondent	Interview Extract
<p>A_8</p> <p>Couple share responsibility for asthma care. Although different in coping style, they usually share similar beliefs about management, and can support each other.</p>	<p>F: Apart from practical things, I mean it [asthma care] does provide a potential area of disagreement over how to treat certain issues.</p> <p>M: Yes.</p> <p>F: And how serious a situation is, for instance, which has certainly happened. Not so much more recently.</p> <p>M: No, I don't think so.</p> <p>I: Well, you think she should be more relaxed about it, or that kind of thing?</p> <p>M: Yeah.</p> <p>F: Well, as it has emerged, [mother's name] is very anxious. She can be anxious about other things, not just this. But, and I have felt sometimes that my less anxious response is unsatisfactory. And I feel drawn towards the anxious state. Do you know what I mean? There's some pressure to become anxious, a bit perhaps by not being so anxious, I'm undermining you in some way.</p> <p>M: But, while I feel that we make up 100%, I think that I'm 75 and he's 25, you know in those situations. And....</p> <p>I: Of responsibility?</p> <p>M: Of anxiety.....I think we cope, well I think generally, although we have a slight difference, I don't think it's a big difference, I think</p>

	<p>we're pretty much, I think we have pretty much the same attitude towards the things that he can and can't do. I don't think [father's name] is any more or would be any more relaxed about him, say for example, going to somebody's house who's got cats than I would, would you?....I feel that, you know, generally, we are, I feel positive about the fact that we both, whether it's right or wrong or whatever, have the same attitude towards his asthma, rather than constantly having a ...although I might be slightly more anxious, I think in general our attitude about his asthma management and things like that is pretty much the same.</p> <p>F: Yup. That's right about the asthma management. I think we've, I think we've had differences about the going out business. You know, I don't mean about going to other people's houses, but, well about eating, about eating out.</p> <p>M: Yeah, I'm better about that.</p>
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This couple, and A_13 sometimes had areas of disagreement about asthma care, but recognised why and were able to resolve their differences. This helped the couples to feel 'positive'; possibly the father's more measured approach in crises was helpful and supportive. Also, the father and mother of A_8 recognised their differences in coping styles and were able to discuss how to take account of these differences when dealing with stressful situations. This may be an important factor when considering adjustment of parents where the couple share care management.

Mother is respondent: Diabetes Group

Separated or divorced mothers (Diabetes Group)

Two mothers in the diabetes group were divorced or separated (D_9, D_15), which happened in both cases before the child was diagnosed. One mother was widowed (D_7) and none of these mothers currently had partners. The mothers of D_9 and D_15 had minimal contact with their ex-husbands, who occasionally looked after the child; however, the mothers believed they were not competent in diabetes care, and this experience was stressful. All three mothers expressed the need for extra support and to have someone to talk to about their experiences and needs. The excerpt from D_7 is an example:

Respondent	Interview Extract
<p>D_7</p> <p>Parent feels unsupported</p>	<p><i>Referring to coping with child's diabetes:</i></p> <p>I: That's quite hard really, isn't it?</p> <p>M: That's what I'm saying. If I had a husband around – if he was still around, at least I'd have got support. This is why.... I'm probably making it sound an awful lot worse than what it is, but it's because – well it is awful, it is an awful thing to have. There's no nice thing about it. But it just seems worse for me because I have to deal with it on me own along with everything else that I have to deal with.</p> <p><i>Referring to an incident of her son's non-adherence:</i></p> <p>M: I knew it would be me that would have to pick up the pieces. I'd have to, you know, I know it all sounds very selfish – I keep saying 'me', but I mean I suffer with depression, I've been on antidepressants. You know, I've brought up 3 kids on me own, and he [diabetic child] just seems to keep wanting to make life difficult all the time. It was just one extra thing we had to deal with.</p>

Mothers with a partner living in the household – partner involved in caretaking (Diabetes Group)

Of the five mothers who reported that their partner was involved in caretaking, two explained that each had different responsibilities, but that the mother was responsible for the diabetes management (D_1, D_2), one said they were equally shared (D_3) and in the final two cases (D_6, D_10), that the father undertook some diabetes care, but the mother had the main responsibility.

In the two cases where the mother undertook diabetes management, this seems to have been a case of an agreed 'division of labour' (as in the example of A_12, reported previously). Both mothers appeared satisfied with this and did not report stressful aspects of their partner relationship.

A similar case as reported in the asthma group was found with the respondent D_3, with regard to disagreements with her partner regarding treatment management. This caused some stress in the relationship, particularly in the early months after diagnosis:

Respondent	Interview Extract
<p>D_3</p> <p>Shared diabetes management – disagreements over diabetes care</p>	<p>M: I must tell you about my husband on this, because he was very, very upset, because I think again, you'd rather have something yourself than have your child have it. And we took turns to do her injections until she gave them herself after several months. My husband would do the morning, for work reasons, and I'd do the evening. And I think he was certainly as upset and emotionally sort of, I don't know, knocked sideways really. He is by profession a computer engineer and he's very accurate and precise in his work. And why I'm telling you that is, because as much as he hurt about it, he wanted us to follow the rules absolutely.</p> <p>So when we were given our diet sheet, we measured and weighed things to try and get used to portion sizes. And I know we argued; it's awful; we argued about the size of this custard dish, because I can't honestly remember how many portions it was, but I said, 'Oh, one more spoonful won't harm'. And he said, 'No, it says there's...' You know, it's this stupid, ridiculous situation, but you know, you're suddenly given this set of rules to follow and because of the nature of his work, he would follow them to the letter. But me thinking, 'Oh, my child's hungry, so pop in a spoonful of pasta!' (laughs)</p> <p>And it just caused an argument that we wouldn't normally have had. And you think, 'Oh my golly, this diabetes has made us not get on with each other, which is horrid'. And I don't like that. And you actually find that your own relationship is quite tense, because you're wanting to do what's right for the hospital, what's right for your child, what's right for your husband. He's trying to, you know... I think perhaps again, you have to go through that experience, but those bits you don't know about until you're actually in the situation. And obviously now, we know that it doesn't matter whether you have a spoonful of pasta or not, but you see on early diagnosis, you're given these procedures and you're told this stuff, and you just want to do what's right, because you feel it will have such a lot of impact on this situation.</p>

In the final two cases, different feelings were expressed about the father undertaking some diabetes management. In the case of D_6, the mother did not welcome the father's involvement, which she thought was not competent. When he 'interfered', she said she 'shouted at him' and told him to 'get lost'. In contrast, the other mother (D_10) and her husband agreed about the child's diabetes care, and the mother felt well supported, particularly when the husband was competent and calm, as shown in the following excerpt:

Respondent	Interview Extract
<p>D_10</p> <p>Father has some involvement in diabetes care – mother feels well supported</p>	<p>M: Um, I think [husband's name] has made it better for me, because he's positive and he was very quick at taking everything on board, right in the beginning. That definitely made it easier for me and for [child's name] I suppose really....My husband takes things on board really well. You know, at doctor consultations and things like that, he tends to, but I don't feel as though I am taking them in as well as he does.....</p> <p>[Husband's name] is just wonderful. Well, you know, he'll just get on with it. I know deep down, he feels awful a lot of the times, but actually the way he comes over isn't.</p>

Mothers with a partner living in the household – partner not involved in caretaking (Diabetes Group)

Two mothers reported that their husbands were not involved in the diabetes management, which they said was due it being easier for the mother, the long working hours of their husband (D_11 and D_16), and in the former case, recent mental illness. As with the mothers in the asthma group, mothers in this situation would like to have been better supported, as implied in the following excerpt by D_16:

Respondent	Interview Extract
<p>D_16</p> <p>Not sharing care, mother feeling it has been 'left to her'</p>	<p>I: And your husband, does he get involved at all?</p> <p>M: Not really. (Laughs).</p> <p>I: How does he feel about it?</p> <p>M: Um, I think he feels the same as me. I don't know whether he still realises how, you know, upset I can get. (Begins to get tearful). But, you know, he just leaves it to me really.</p> <p>I: Hmm. So he doesn't do any injections or help with blood tests or things like that?</p> <p>M: No. No. No. It's not that he wouldn't. It's just because he's always working, well you know what it's like, it's easier for the person that's at home.</p>

Both mother and father are respondents: Diabetes Group

In six instances, mothers and fathers were interviewed together (D_4, D_5, D_8, D_12, D_13, D_14). In all of these cases, the parents said they shared the same responsibilities; the father was an equal partner in the diabetes management. In some cases, similar issues about disagreements concerning diabetes care were discussed as in the excerpt of D_3 above (D_4, D_5, D_8). These generally were not long-term, ongoing disagreements (e.g. shortly after diagnosis or after a serious episode), and tension between the couple seemed to be short-lived or not serious. The exception was in the case of (D_4), who reported ongoing disagreements and conflict about the child's eating, which they said resulted in a strain on the marital relationship. Also, the husband felt somewhat neglected due to the degree of attention given to the diabetic child:

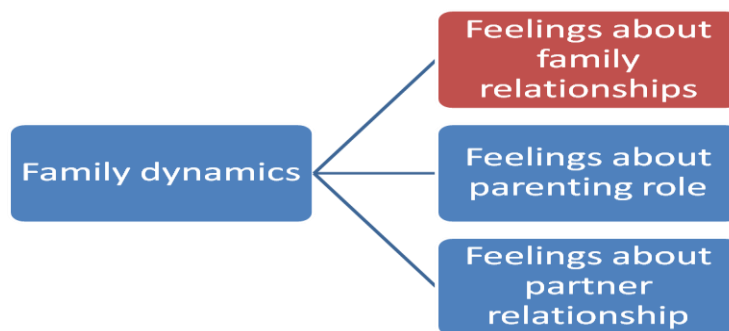
Respondent	Interview Extract
<p>D_4</p> <p>Disagreements about diabetes care is a source of conflict – diabetes puts a strain on relationship; father feels neglected</p>	<p>M: Well, you think that I'm overly anxious, for example if we go somewhere, I'll take lots of different food. To me, the main thing is that [child's name] eats when he's supposed to. I don't care if I have to cook him five different meals, whereas [husband's name] says, 'Oh, just give him one thing – eat it'. So... Well, it's true.</p> <p>F: It's a point of conflict.</p> <p>M: I think that if there are any strains in our relationship, then this [diabetes] puts more strain on it. It makes it more difficult. Just like little disagreements we have about eating and so on. (laughs)</p> <p>F: No; it's something major and problematic. You're very obsessive...</p> <p>M: I'm not obsessive.</p> <p>F: ..and your total interest is understandably the little boy, and nothing else really matters.</p> <p>M: That's not true.</p> <p>F: It is true.</p>

Even when there were not disagreements about diabetes care, the demanding nature of treatment, particularly when the child was non-compliant, was reported by one couple (D_14) to have stopped them working on their own relationship (where they said they had some issues to resolve).

7.6 FAMILY DYNAMICS – ISSUES UNIQUE TO EACH DISEASE GROUP

Of the three sub-themes relating to family dynamics, feelings about family relationships was the only one where unique, disease-specific factors were identified. Therefore, there will be no reference to parenting role or partner relationships in this section.

7.6.1. Feelings about Family Relationships



Asthma Group

Some group differences were noted in relation to changes experienced in the relationships within the family in the course of the child's illness. (For details, see Appendix 7.7). In particular, parents in the asthma group commonly reported, in the context of the 'core' family and to some extent, the extended family, becoming emotionally closer and more protective of each other. This seems to have occurred after significant asthma attacks, that were often life-threatening (A_7, A_12, A_15); also, sometimes parents developed a greater awareness of how 'precious' were all the children in the family (A_9, A_11), possibly triggered by the threat to the life of one of the children. Two mothers said they felt somewhat closer to the asthmatic child than the other children in the family (A_5, A_7). This tendency for changed relationships is illustrated by the following excerpt:

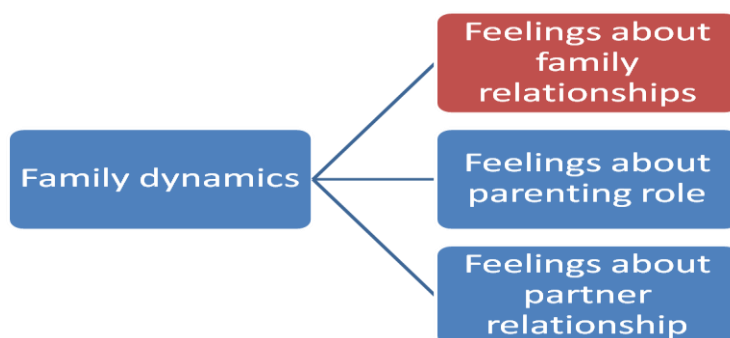
Respondent	Interview Extract
<p>A_12</p> <p>Family ‘closer’ and more emotionally demonstrative after serious asthma attack</p>	<p>I: Do you think that the relationships within your family have changed since, I suppose since [child’s name] became significantly worse?</p> <p>M: Yeah, I do. I think we were always a close family, and a very loving family, you know, demonstrative as it were, and cuddly and things. But it’s actually made us even, even closer. [Sibling’s name] is always cuddling and touching [child’s name]. I think it’s a security thing. I’m not quite sure it’s always a healthy thing, but at the moment she’s.. they’re very cuddling and close and you know, they like to be together a lot more.</p>

Diabetes Group

Such relationship changes as described above were not reported in the diabetes group. However, one parent said that initially, the family had focused their lives and activities around the diabetic child, then realised this was not helpful for the family (D_3). In one other case, the parent said the family did what was best for the diabetic child (D_11). For details, see Appendix 7.8.

7.7 SUMMARY AND DISCUSSION OF SIMILARITIES AND DIFFERENCES IN FAMILY DYNAMICS

7.7.1. Summary and discussion of similarities and differences in feelings about family relationships



In both the extended and 'core' family, parents often spoke about how members supported each other, such as by 'pulling together' and being available to offer practical or emotional help. There is evidence from the data that parents found it a great relief to know that there were others on whom they could rely, particularly at difficult times. Such relatives, commonly grandparents, were often very aware of the nature and management of the illness, and the need to offer support.

However, parents also said that some family members (usually of the extended family) were not 'capable' or 'understanding'. Sometimes these two factors were associated, i.e. unless they were 'capable' in disease management and had experienced at first hand what the parent had to cope with, they couldn't fully 'understand'. A number of parents also said some relatives offered help only if there was a crisis, which could reflect a lack of appreciation of the day-to-day stressors involved in caring for children with a chronic illness. There is evidence that these parents found this stressful and felt the lack of this support.

A finding that was specific to the asthma group alone was reports of changes in family relationships following serious asthma attacks. Parents described how families became closer, and sometimes more emotionally demonstrative; in other cases, the mother and asthmatic child felt particularly close, with other members being more distant. Some other respondents described how they had a greater appreciation that all their children were 'precious'. Such reports were not given by parents in the diabetic group, possibly because life-threatening episodes had not been experienced. As mentioned previously, the unexpected, sudden, severe and unpredictable nature of some asthma attacks may be particularly likely to precipitate feelings of insecurity and attachment behaviours.

7.7.2. Summary and discussion of similarities and differences in feelings about parenting role

No unique issues were identified in the parenting role specifically relating to only one of the disease groups. Therefore, only the similarities and differences noted within the common areas identified will be discussed.

Parents in both groups expressed both positive and negative feelings about parenting. On the negative side, some parents expressed feeling alone, or the belief that others did not understand their difficulties as a parent. Positive expressions mainly related to feeling pride and pleasure when their child had overcome obstacles of their illness to achieve something.

Whilst other parents might have such feelings, these might be particularly significant for respondents because the achievement may have been harder for their child to reach than for unaffected children.

Many parents described how they encouraged, supported and educated their children (for example about their illness). The latter was sometimes a challenge because although they tried to offer explanations in a developmentally appropriate way, they realised that child could not always grasp these explanations. For example, although parents of diabetic children tried to explain reasons for the diet to their child with reference to long term risks, they recognised that the child could only appreciate short term displeasure.

A number of issues were expressed by parents in relation to treating their child as 'special' or 'normal'. The most common of those points relating to treating as 'special' was the concern that they were overprotecting their child; a number of parents were concerned that this would hamper their child's development or experience of childhood. This was more often expressed by parents in the diabetic group, possibly because there were more children in this group who were older and who would therefore be developmentally capable of being independent. Alternatively, parents of diabetic children may have been more worried about their child's ability to avoid risks to their health (for disease or treatment-related reasons) when allowed to be more independent.

Also in relation to the issue of parenting their child as being 'special', a few parents talked about concerns about 'spoiling' their child, believing they had been too lenient or sometimes had let their child get away with too much misbehaviour. Sometimes parents found it difficult to discipline their child when unsure of the cause of the behaviour (i.e. illness-related or not).

Other parents felt that the illness did not affect the way they dealt with behavioural problems, saying they were firm, or used rewards or punishments. Some parents of diabetic teenagers felt that they 'nagged' them too much about their medication or treatment, which sometimes led to unpleasant confrontations with their teenager.

Throughout this section, it has been apparent that many of the feelings or challenges described by parents were those that may often be experienced by parents of unaffected children. However, the illness or treatment created a further dimension to these issues; on the positive side, parents whose children have been able to overcome adversity may feel more positive than other parents, whilst others may need additional support to manage these challenges.

7.7.3 Summary and discussion of similarities and differences in feelings the partner relationship

Parents in both groups included both those who were within and those not within a current relationship with a partner. Mothers who were single parents tended to report that they missed having support from a partner. This feeling of not being well supported and understood was reported by some mothers from the diabetes group whose partners did not participate, or minimally participated in care giving activities or diabetes management. It may be that by participating in treatment management, both partners can gain a better appreciation of the stressors and demands of this responsibility. When one partner does not understand and appreciate this, this seems to be a stressor in the relationship of some couples. Some mothers in both groups reported that complementary coping style of their partners was helpful, for example being a calming influence at stressful times.

However, sharing the asthma or diabetes care was not necessarily associated with harmonious partner relationships. To some extent in the asthma group, but more particularly in the diabetes group, having mutual responsibility for treatment management could lead to conflict where there were disagreements about the care. For a couple in the asthma group, this was about eating out in restaurants, and for all of the couples in the diabetes group, this was about food and eating. In most cases, these disagreements occurred shortly after diagnosis, when the parents were getting used to the diet, and feeling quite anxious to get this complex treatment right. In one case, this disagreement related to giving night-time snacks following a recent serious 'hypo'. However, one couple continued to disagree about their child's eating, which, together with related issues, had put a more persistent strain on their relationship.

There were also instances in both groups where couples had negotiated a 'division of labour'; sometimes this meant that only the mother was responsible for treatment management. Although the couples felt this 'worked', fathers might not have the same appreciation of the stressors involved, particularly after serious attacks.

There seemed to be particular circumstances that predisposed couples to report sources of stress in their relationship. In the asthma group, this was after the child had been in hospital or after a persistent period of night-time attacks; the mother's tiredness and treatment burden was probably contributory. In the diabetes group, this was soon after diagnosis in most cases, and related to arguments about diet and eating. Measures taken to help parents better

understand the diabetic diet and additional support for parents of asthmatic children at these times may be beneficial.

7.8 GENERAL DISCUSSION AND IMPLICATIONS FOR THEORETICAL MODEL

This discussion will focus on an analysis of findings relating to Objective 4, which is to: 'Describe and examine parents' experiences since their child's diagnosis, in relation to their personal and family life, employment and leisure'. There is some overlap from previous chapter findings; parents' personal and family life is inevitably inter-twined with the child's social life, behaviour and illness management.

As illustration, similar findings concerning parenting that have been highlighted in this Chapter were also identified in Chapters 4 and 5 in relation to decision making about supporting children's development and social lives and managing illness. Therefore, some of the schematic diagrams used in this Chapter to illustrate findings will draw on findings from outside this Chapter. Key questions to consider in this discussion include: How do parents' personal and family lives reflect and influence their adjustment? What are the features of and influences on parent-child dynamics within parenting behaviours that are important for parents' adjustment?

When examining findings about parents' personal life, it is clear that a range of factors affect parents' experience of satisfaction and stress. This is illustrated in Appendix 7.13 on page 192, where Schematic Diagram 25 shows the multiplicity of negative and positive influences on parents' personal lives. Supportive interventions that focus on facilitating positive aspects of these factors will be beneficial for parents; some of these require practical external intervention such as helping parents to apply for a disability allowance or assisting with finding suitable child care. Avoidance of negative health experiences may also reduce the likelihood of parents undertaking anxious monitoring of the child's health state (see 'preoccupied' in Diagram 25). This also highlights those parents who might be at higher risk of mental health problems due to excessive stress, so enabling better use of scarce psychological intervention resources.

Although no diagram has been constructed concerning parent and family leisure, results from this chapter suggest further supportive interventions that may be beneficial for parents, particularly with regard to providing realistic planning support (e.g. for diabetic group about

regulating insulin on holiday, and for asthma group, easier access to necessary emergency medicines, foreign language medical terms).

In Appendices 7.14 and 7.15 on pages 193 and 194, the impact on family life and its relevance for parents' adjustment are illustrated in Schematic Diagrams 26 and 27. These diagrams reflect the findings that a source of anxiety for parents is the impact on siblings in the family. Diagram 26 shows the importance of preparing siblings (and not just parents) for the range of symptoms that might be observed by the chronically ill child and their significance. For example, siblings of an age where they would be able to understand could be told that, although unlikely, a diabetic child could lose consciousness because of a 'hypo' (i.e. they are not dead, as some siblings thought), and that an injection [of glucagon] (which parents have) will revive them. Therefore, the unexpected witnessing of an unconscious sibling would be less distressing for them. In turn, this would be less distressing for parents, who were worried about continued anxiety of siblings.

A different issue is illustrated in Diagram 27. Although in most cases siblings were supportive (as shown at the bottom of this diagram), and this typically had positive outcomes for both the sibling and parent, the model at the top of this diagram shows the rare instances when this was not the case (e.g. D_15). Clearly, this has more negative outcomes for parents' adjustment; they experience high stress and low self-efficacy. Furthermore, sibling-child conflict associated with this pattern is not beneficial for the child's mental or physical health, which is an added stressor for parents. This diagram has significance for points made in this Chapter about parents treating children as 'special', as this scenario would be less likely if the sibling did not perceive that their sibling was treated as 'special', while they were not.

Diagram 27 makes reference to the phrase, 'Family ethos of pulling together'. Many parents expressed that this was the way their family functioned, particularly at the start of the illness experience. This could be a motivating factor for sibling contributions to medical care; also, the value given by the family to mutual support could add to the parent's reinforcement of the child's altruistic behaviour.

When examining parents' descriptions of family life and family relationships, a very common ethos of the core family seemed about 'pulling together'; this phrase was used often by parents. In Appendix 7.16 on page 195, Schematic Diagram 28 shows that whilst many aspects of this ethos are beneficial for parent and family adjustment, there was potential for negative outcomes.

For example, the results from this Chapter showed that some parents (e.g. D_12) believed that the siblings should not have sweets, in order to show empathy with the child with diabetes; on the other hand, only the diabetic child was allowed night-time snacks. This led to parent-sibling friction and stress. On the other hand, where parents allowed sweets for the siblings and persuaded the diabetic child to have alternatives (or smaller quantities) (e.g. D_6), sibling conflict over sweets was not reported. This family showed empathy and support in other ways, such as through family involvement in illness charity fundraising activities. There is a similar sibling issue for the asthma group, i.e. whether everyone has activity restrictions (e.g. going horse riding), or only the asthmatic child. A key difference between families with less or more conflict seemed to be about whether the child's illness was the central focus of the family (less positive) or whether all family members' needs were considered together (more positive).

Other negative and positive outcomes related to the impact on partner relationships, as at times, one partner's needs were perceived to have been neglected (often the father). Some parents reported that they felt this had contributed to the break-up with their partner. Another aspect of 'pulling together' was whether medical care and parenting responsibilities were shared and negotiated. In some families where sharing did not occur, this was a source of conflict with a partner (possibly because one parent – normally the mother – felt an excessive burden). In general, parents who reported equal sharing of care management said this was mutually beneficial, although in some cases, parents said this was sometimes a source of disagreement and conflict, although in most cases short-lived.

Finally, some parents reported that where the child's illness continued to be intrusive in family life (e.g. continued attacks, severe and frequent symptoms), it became more difficult to 'pull together', and family conflict increased. Possibly one reason for this is that the family members did not perceive positive outcomes of their efforts; another possibility is that the chronic stress might have made it more difficult to 'pull together', and behave in an altruistic way. This may have significance for identifying families that may be having more difficulty – i.e. not necessarily those with more severe symptoms, but those where symptom control is not good. On the positive side, parents also described the benefits of a closer 'bond' among family members, particularly where there was a good outcome in the face of emergencies or particularly difficult challenges.

With regard to the extended family, 'pulling together' was also reported by some parents when describing wider family functioning. In Appendix 7.17 on page 196, Schematic Diagram 29 shows that this was perceived by parents as being very beneficial for reducing

their stress. It would be interesting to know the perception of extended family members, who might feel that all the support is one-way. Nevertheless, this supportive extended family functioning makes it likely that it is a very important feature contributing to positive parental adjustment. Other parents described extended family member behaviour as less supportive. This pattern of functioning has been termed ‘detached’, because of parents’ descriptions of little involvement or investment in supporting the core family. This was perceived by parents as detrimental to their coping or they had neutral feelings about it. In the latter case, it was often where there was good core family support and extended family were elderly or not considered to have potential to be capable of providing support anyway (even if they wished to do so). Some ex-partners (i.e. child’s biological father) were also described in this way. Thus, this pattern of family functioning may be more relevant when considering parents’ adjustment where supportive resources available to the core family are limited.

The second question posed above was, ‘What are the features of and influences on parent-child dynamics within parenting behaviours that are important for parents’ adjustment?’. In Appendices 7.18-7.20 on pages 197-199, Schematic Diagrams 30-32 highlight important findings from the data analysis. Diagram 30 refers to how normal parenting concerns such as supporting and protecting a child from stress are magnified when the child is exposed to repeated stress (for example hospital admissions). Developmental issues, such as limited abilities of young children to understand meanings of events and express feelings and ideas, contribute to the parenting challenges faced by parents of young children. Some issues raised in Chapter 4 about parenting challenges in managing children’s behaviour are reiterated in this diagram. Ineffective management of challenging behaviour can lead to high parental stress and low self-efficacy.

Some findings of Chapter 4 concerning parenting of children experiencing social restrictions have also been included in this diagram. This is a reminder of the significance of illness-related variables (such as predictability of symptoms), and teachers’ and child’s competence, but in the context of how this can lead to low or high parenting self-efficacy.

In Appendices 7.18 and 7.19 on pages 197 and 198, Schematic Diagrams 30 and 31 show how there are added dimensions to normal, developmentally-related parenting goals for older children and adolescents such as supporting and protecting the child from excessive stress, keeping them safe and supporting their development. Added to this are illness-specific concerns about threats to the child’s health and development. Diagram 31 uses the illustration of the experience of bullying (reported by D_8), which resulted in school refusal. Whilst this would be a concern for children unaffected by a chronic illness, parenting challenges are exacerbated by parental worries about illness control. Although this example is of a diabetic

child, it could also apply to a similar situation with an asthmatic child since emotional stress can exacerbate asthma symptoms. Depending on the outcome of the incident, parents' stress may be relieved or increased.

In Appendix 7.20 on page 199, Schematic Diagram 32, which relates specifically to parenting goals of promoting independence and protection, draws on some of the findings from Chapters 4 and 5 concerning the experiences of the child's social life and illness management. However, these issues are re-examined in the context of parenting tasks. A range of illness and treatment-specific factors influence parents' responses. For example, whilst parents and diabetic adolescents often commented favourably on how the change to a 'basal bolus' system helped to promote the adolescents' control and decision making, the reduction of control for the parent could be stressful if the adolescent is not viewed by them as being reliable in treatment management.

This diagram also illustrates how limits on the child's independence are not necessarily due to parents being 'overprotective', i.e. restrictions may be totally appropriate given the high risk. Nevertheless, a pattern was often observed where the parent had a high degree of monitoring and 'nagging', which was associated with adolescents' resentment and parent-adolescent conflict. A number of parents expressed worries about being 'overprotective', i.e. being faced with a dilemma of choosing between low risk / high intrusiveness versus high risk / low intrusiveness. This group of parents and adolescents may benefit from more focussed support, as they are likely to be more anxious and less satisfied with parenting and health care outcomes.

Key insights relevant to the theoretical model

How parents' personal and family lives reflect and influence their adjustment

- Sibling anxiety is a source of parent anxiety, but there is scope to prevent or minimise this
- Some patterns of sibling-parent-child interactions may be less conflictual than others, especially where parents recognise and respond to each child's need. Supportive siblings contribute to more positive feelings and lower stress for parents.
- Single parents tend to experience particularly significant adjustment difficulties where there is limited family support

- A core family ethos of ‘pulling together’ is generally beneficial, but there are factors that can lead to more negative outcomes.
- An extended family ethos of ‘pulling together’ is more beneficial than a ‘detached’ ethos, particularly where the core family coping resources are limited.

Features of and influences on parent-child dynamics within parenting behaviours that are important for parents’ adjustment

- Parents of children with diabetes or asthma have parenting concerns relating to the child’s illness that are additional to those experienced by parents in general.
- Making parenting decisions requires difficult judgements involving balancing risks and benefits.
- The timing in the child’s development is often a feature of this time of difficult decision making (e.g. protecting from emotional stress for very young child, promoting social activities and social competence for school child, promoting independence for adolescent)
- Adolescence appears to be a particularly significant focus of parents’ parenting concerns and worries about overprotecting / not promoting independence. Likewise, adolescents can find it difficult to accept parents’ apparent intrusiveness. This group of parents may be particularly vulnerable to stress and low self-efficacy, particularly where there is poor treatment adherence by adolescents.

CHAPTER 8: DISCUSSION

8.1 INTRODUCTION TO THE DISCUSSION

In this final Chapter, the study objectives will first be revisited. Following this, findings from all previous chapters will be integrated and used to formulate and propose new theory relating to the study objectives. The new theory will be comprised of a number of components. Firstly, a set of fifteen theoretical propositions will be presented, which are based on key findings from each chapter; these will be presented following a brief discussion of the related findings. These theoretical propositions were developed from the thirty-two schematic diagrams that integrated and synthesised study findings in each chapter.

Through the process of reviewing key insights from each chapter, schematic diagrams and theoretical propositions, new over-arching themes were identified. These themes are used as a framework through which the findings from all chapters can be viewed. Appendices 8.1-8.4 will be used to show how these new, over-arching themes are threads that are woven through all of the study findings concerning parents' adjustment. The over-arching nature of these themes is demonstrated through mapping these against the study objectives, schematic diagrams and theoretical propositions. Finally, a theoretical model will be presented that emerged from all of the above processes.

Following the presentation of the theoretical model, further published research literature will be considered that might support or refute the theoretical propositions. The significance of these other research findings will be discussed, as well as strengths and limitations of the study and of the new theory. An analysis of the credibility and rigour of the methodology of this study will also be undertaken. Recommendations will be made with regard to how the theoretical model and its underpinning propositions may be used in future research and clinical practice.

8.2 REVIEW OF THE STUDY OBJECTIVES, PRESENTATION OF RELATED THEORETICAL PROPOSITIONS AND NEW THEMES

The objectives of this study, presented in Chapter 3, and considered in subsequent chapters were as follows:

- 1) Examine similarities and differences in parents' perceptions of the impact of the illness on the child's emotional and social life; consider how these perceptions influence parents' practical and emotional responses.
- 2) Examine similarities and differences in illness features and the illness management experiences of child and parent; consider the significance of these for the child's and parent's adjustment.
- 3) Examine the parents' experience of the effects of the child's illness and its management over time, as the years since diagnosis increase and as their child develops and matures.
- 4) Describe and examine parents' experiences since their child's diagnosis, in relation to their personal and family life, employment and leisure as well as relationships with staff from the child's school and health services.
- 5) Ask questions about the data to explain similarities and differences in parental coping and adjustment, and how and why this changes.
- 6) Discuss the findings and theoretical model, and the implications for future clinical practice and theory development.
- 7) Examine the psychological concept of adjustment and discuss its meaning in relation to parents of children with Type 1 diabetes and asthma.
- 8) Identify which parent behaviours may be reflective of better or less good adjustment, and any predictors of adjustment.

Whilst most of the above objectives were explicitly revisited in one or more of the results chapters, Objectives 5, 7 and 8 were threaded throughout, and findings will be drawn together in this Chapter; therefore, these will be discussed after Objective 4. Key insights together with important elements from the schematic diagrams of each chapter will be incorporated into the discussion of each objective. Objective 6 will be briefly considered in this section, but will be discussed further, as it is the central purpose of this Chapter.

Objective 1: Examine similarities and differences in parents' perceptions of the impact of the illness on the child's emotional and social life; consider how these perceptions influence parents' practical and emotional responses.

Chapter 4 began to examine parents' views about their child's adjustment, and this was found to be a very important factor influencing parent's own adjustment. Parents discussed their child's adjustment in both context-specific and general ways. Context-specific issues related to the degree to which the child was able to participate in social activities (particularly of the type that were important to the child). As the child grew older, children and their parents felt it was important to undertake these activities (such as sporting activities and school trips) without parents being present. Both children and parents viewed these activities as contributing to a highly desired perception of 'being normal'. Where children had limitations in their desired social activities (especially where child desire was intense), child disappointment was felt deeply by parents, who expressed sadness and sometimes distress at not being able to offer these opportunities. These feelings might also be related to parents' views of the requirements of their parenting role (to be discussed later).

(i) Adjustment is dynamic not static, and varies with situations and time in the illness course.

Other context-specific factors influencing children's adjustment included hospitalisation; some parents perceived that their child adjusted poorly to being in hospital (for example due to fear of having procedures involving needles or masks), but outside these experiences coped well in daily life. Exceptionally, a parent of a young child with repeated hospitalisations with asthma reported child internalising behaviour. Where parents also had fears of such procedures, they also experienced distress and an inability to support the child. Thus, in both of these groups of examples of context-specific adjustment, where parents felt unable to provide for their child's needs, they experienced personal distress and anxiety, disappointment, sometimes self-blame and low self-efficacy. Therefore, the following theoretical proposition about parental adjustment is made:

(ii) Parents' adjustment is related to the degree to which they are able to provide emotional support and facilitate experiences perceived by their child and themselves as necessary to 'be normal'.

Related responses of parents concern this belief in the importance for the child as far as possible to have a normal social life. Nevertheless, parents worried about health risks, particularly where the child had not demonstrated good levels of personal responsibility and self-care. Thus, parents needed to sometimes make difficult judgements about degrees of risk in allowing their child to undertake activities. Estimating risk as being high led to more social restrictions for the child, but also parents often felt guilty at denying the child the opportunity. Sometimes it was not the parent's decision but others (e.g. school staff would not give treatment on a school trip). This experience was evidently a source of stress and guilt for some parents. Thus, another theoretical proposition relating to this objective is:

(iii) Parents believe that social participation is a requirement for positive adjustment, but they do not believe it is always safe for the child. Worry about safety can be associated with allowing it, but worry about social development if not allowing it.

General aspects of children's adjustment were also discussed by parents, such as whether or not the child showed behaviours that could be described as internalising or externalising. Parents attributed both adaptive and maladaptive behaviour to both external and child internal factors. These included developmental stage (i.e. angry, aggressive behaviour seen as developmentally normal for a 4 year old when denied something they wanted), child's temperament, prior experiences (e.g. bereavement), or features of illness including symptoms (e.g. hyperglycaemia in diabetes or hypoxia in asthma making the child exhibit oppositional or other externalising behaviour) and medication.

Parents' attributions in some cases were not certain (e.g. was the child deliberately being oppositional, or was the behaviour due to symptoms?), and in others not under their control (e.g. perceived medication ineffectiveness). Where parents felt they were unable to determine and/or where the cause of the behaviour was not able to be influenced by the parent, they felt less able to influence the child's maladaptive behaviour. This leads to the next theoretical proposition about parents' adjustment:

(iv) Parents identify internal and external factors that they believe influence children's adjustment. Parents' adjustment is related to the degree to which they can confidently identify and control causes of less adaptive child behaviour.

Parent's practical and emotional responses to their child's adjustment-related behaviour were influenced by the meaning attributed to the behaviour and their assessment of the child's internal state. For example, the child's 'negative talk' was interpreted positively by some parents (as a useful, temporary coping response) and negatively by others (as a reflection of deep-seated psychological problems or depressive symptoms, and a more enduring problem). Parents who saw this behaviour in a negative way tended to exhibit more worry, distress and sometimes self-blame because they perceived they had not fully met the child's needs. Parents who viewed such behaviour as positive also believed that the child had resilience factors that were able to counteract the negativity (e.g. had a 'sunny disposition') and / or that this was a temporary behaviour on a 'bad day'. Generally, parents viewed 'positive talk' as a sign of good adjustment.

Parents also had different responses and interpretations concerning their child's desire to be open or private about the illness or treatment. This is partly explained by the child's and parent's views about how others would respond to the child being open. One reason for differences in parents' perceptions was whether they believed openness would negatively impact on others' perceptions of the child as being 'normal'. There was some evidence to suggest that where parents viewed the child as popular and accepted by peers, openness was encouraged and was felt to be unlikely to have negative consequences for the child's acceptance by peers. Some parents saw the child's desire to be private as acceptable, whilst others thought it was less desirable from both a social adjustment and safety perspective (i.e. if they collapsed, nobody would know why). This was therefore a source of worry for some parents. This leads to the next theoretical proposition:

(v) Parents interpret the meaning of their child's verbal and behavioural expression about the illness as either adaptive or not. Negative interpretations are associated with parents' worries about the child's emotional state, psychosocial adjustment and personal safety. Positive interpretations are associated with parents' estimates of their child's resilience and optimistic feelings about the child's adjustment.

Objective 2: Examine similarities and differences in illness and treatment features and the illness management experiences of child and parent; consider the significance of these for the child's and parent's adjustment.

Effective symptom control and treatment management is an important goal for parents in both illness groups. The ability for parents and children to manage the illness effectively is

affected to some degree by the features of the illness and the challenges and complexity of the ongoing treatment to maintain health and prevent or manage exacerbations / attacks. It is also affected by individual, interpersonal and external factors. Some differences in the features and goals of treatment of the two illnesses are significant for child and parent coping and adjustment.

Firstly, the goal of asthma management is to maintain good lung function and prevent asthma attacks. If asthma attacks occur, the goal is to intervene as quickly and effectively as possible to stop the attack. Once stopped (e.g. usually through use of a 'rescue' or 'reliever' inhaler), the beneficial effect is immediate and obvious for parent and child. Whilst good lung function is a long term goal, it does not seem to have the same sense of priority and focus for parents as the more immediate prevention and management of acute attacks. This might be because attacks can be severe and life-threatening (so instilling a sense of high priority in prevention and management), but also that lung function is less observable and easily assessed. (Peak expiratory flow meters, used to assess lung function, are not generally viewed by families and doctors as highly reliable); otherwise parents' assessments are based on subjective observations.

These factors are of psychological importance because it is much easier to see cause-effect associations when they are closely linked in time. Also, the action (giving an inhaler) is not difficult and normally has a high degree of effectiveness. Similarly, knowing a trigger of an attack to be a particular allergen (e.g. horse hair), then observing an immediate asthma attack reinforces that that allergen should be avoided. Therefore, in either of these cases, there will usually be immediate, effective feedback on the child's or parent's behaviour. This is not only reinforcing but leads to a high sense of parent and child self-efficacy. On the other hand, some children and parents in this sample did not know the triggers for their asthma, and the medication was not necessarily effective. This is believed to be a factor contributing to less good child and parent adjustment (to be discussed later).

This is contrasted with the goals of diabetes management which is to maintain good blood glucose control. Unlike in the case of asthma, this is the central focus for most parents, who recognise and are acutely aware of the potential long term effects of poor blood glucose control. Whilst feedback on current blood glucose values is available from regular blood tests, it is not always obvious what has led to this state (i.e. a combination of multiple factors, not all of which would have occurred immediately previously).

Furthermore, feedback on long term glucose control is normally only available at periodic clinic appointments. Therefore, treatment does not necessarily give immediate and obvious feedback that would strongly reinforce certain behaviours. Whilst it is true that a further goal of treatment is to prevent 'hypos', mild to moderate 'hypos' are quite normal and indeed desirable. According to DN_2, one of the diabetes specialist nurses interviewed, the clinic staff regard having mild hypos as a sign of good control (because it otherwise means the blood glucose is probably too high). Prevention of severe 'hypos' is however a treatment goal. In addition, many parents found that the HbA1c value found at clinic did not correspond with their expectations. The less obvious and non-immediate and sometimes apparently tenuous cause-effect relationships between treatment and outcome means that treatment adherence is less reinforcing for child and parent, and they are less likely to have such a strong sense of self-efficacy in treatment as do many of those in the asthma group.

The findings from this study support that preventive behaviours (particularly those where an immediate serious consequence from its omission is seen) were carried out more consistently by children in the asthma group. No diabetic child completely adhered to all aspects of treatment management whereas some asthmatic children did. These differences in treatment adherence are also likely to be the case because the demands and unpleasantness of the treatment is greater in the diabetes group. Where parents and child believed that adherence was good, but outcomes were not, parents found this very stressful (particularly if there were significant health consequences). Thus, the following related theoretical propositions are offered:

(vi) Where cause-effect relationships are clear, and parent actions are effective, self-efficacy will be greater and anxiety lower than where this is not the case.

(vii) Increased likelihood of the child adhering to treatment will occur where triggers / precursors of a health outcome are known, can be predicted and where the action has an immediate effect, or the omission has a serious immediate consequence.

As well as illness-specific factors influencing treatment adherence, as described above, parents also described internal or external factors. Internal factors included child-specific ones such as age and developmental tasks, temperament and possibly gender. Parents' internal factors included prior expertise and previous success with administering treatment. External ones included prior negative life experiences and perceived burden and complexity of care. For example, doubts about the adolescent's competence and reliability, coupled with parent concerns about the child's internalising or externalising behaviour were related to sub-

optimal treatment adherence and lower sharing of care. Parent worry and low feeling of control were often reported, and likely to negatively influence parents' adjustment.

Better adherence was reported when young children were cooperative and took some responsibility, or in cases of older children, where the parent judged the child to be competent, responsible and have a temperament which was more positive and uncomplaining. This combination of factors, especially if the treatment burden was not perceived to be too great, was more likely to be associated with better treatment adherence and better parent adjustment. Also, parents will be more able to share care more with the child if the child is responsible and adherent. Therefore, the following theoretical proposition is made:

(viii) There will be an increased likelihood of the child adhering to treatment and sharing care where the perceived complexity or burden of treatment is low, where the child is developmentally ready to take responsibility and the parent perceives this is the case. Where care is well managed and monitored, parents experience lower anxiety and greater self-efficacy than where this is not the case. The reverse of this is also true.

Objective 3: Examine the parents' experience of the effects of the child's illness and its management over time, as the years since diagnosis increase and as their child develops and matures.

Parents' experiences at the time of diagnosis normally differed according to the type of illness. One reason was that all of the children in this sample had been diagnosed with asthma at a young age (approximately aged 2) (apart from the one participant where the toddler was awaiting diagnosis, suspected to be asthma). Sometimes parents had expected a diagnosis because of a family history of asthma, so were psychologically prepared, even welcoming of a diagnosis (because it channelled resources for their child to receive specific treatment). Parents' relatives often managed the symptoms well and / or symptoms had declined; extended family members with asthma were usually supportive to the core family, and offered expertise in prevention, symptom recognition and treatment. Few positive models or prior experiences and knowledge of a relatives' diabetes were available to parents in the diabetes group, who generally found the diagnosis shocking. Also, parents found it easier to adjust to their child having the illness when their child was diagnosed at a younger age (as in the asthma group), as fewer family lifestyle changes were required. Therefore, a theoretical proposition is:

(ix) High heritability, low age of diagnosis in childhood, potential for recovery and positive and supportive family members with the illness enable parents to better adjust to a diagnosis than where this is not the case.

It was reported by parents that in the course of both of these illnesses, the child experienced some typical and some atypical illness episodes. Those that were typical were generally better managed because the parent and child had used prior learning from similar episodes to decide how to respond. These experiences were associated with lower stress (except where these were of very high frequency and severity – for example where frequent hospital admissions were normal).

Atypical episodes commonly occurred where the trigger or predictor of an attack had not been identified or the parents' response was ineffective. Therefore these episodes were more distressing, especially if fearful as well (e.g. an attack was life-threatening). Appendix 8.3 on page 206 shows the process that was described by parents when reviewing the events and outcomes of health-related episodes (particularly atypical ones). Parents felt more confident in managing future similar episodes if they had been able to interpret, understand and learn from these experiences for the future, with more positive consequences for adjustment. Where this was not possible, lower self-efficacy and higher anxiety often occurred. Therefore, a further theoretical proposition is:

(x) After unpredicted atypical episodes, particularly where the outcome is fearful or severe, parents search for causes. If the parent believes they can control these in future, they will be less anxious and feel more confident on future similar occasions.

Furthermore, parents described other factors that made their experience less or more stressful. An important one was having a good and trusting relationship with the doctor involved in care during episodes. Also, after episodes, they were more likely to agree with and act upon medical advice.

(xi) Where doctors listen to and respect parents, show empathy, appreciate the parents' knowledge and expertise, give appropriate information and support at the right times and express confidence, parents feel well supported. The reverse is also true.

Within-group and between-group differences were reported by participants in the two illness groups, but particularly in the asthma group. There was a great deal of variability in the features of different children's asthma symptoms, with some children showing seasonal

variability in symptoms, some improving over time, some worsening and some with symptoms that remained consistently mild or consistently severe. Some parents knew the triggers for their child's asthma, whereas others did not. Some children had allergies that caused asthma symptoms whilst others were affected mainly by exercise. However, one feature that stood out as having particular significance for parents was the predictability of attacks. Unpredictable attacks (particularly if severe and frequent) were frightening for parents, especially if the trigger was unknown. These parents were often highly vigilant, expressed more worry than other parents and were more protective of the child.

In the diabetes group there was less symptom variability within the sample. However, some parents believed that their child's blood glucose levels were particularly hard to control, even with their best efforts. Parents of these children may be at particularly high risk of experiencing stress and low self-efficacy (in a similar way to those parents of asthma whose children have poorly controlled asthma, despite parents' best efforts). In this context, it is important to distinguish between symptom severity (where symptoms might be well controlled and predicted) and symptom unpredictability (which might be less severe and not well controlled), because the parent has more control in the former than the latter case. This could be one reason why there has been inconsistency in findings of studies investigating the impact of illness severity on adjustment. The following proposition relates to this point:

(xii) Where the pattern of a child's illness symptoms has features of unpredictability, parent adjustment may be less good than where this is not the case.

Objective 4: Describe and examine parents' experiences since their child's diagnosis, in relation to their personal and family life, employment and leisure.

Parents discussed a number of factors that affected these aspects of their lives, and contributed to their degree of satisfaction and whether they were able to experience relaxation from stress. Factors that were detrimental to experiencing a good personal life were disrupted sleep, financial worries and difficult lifestyle changes. Having unsympathetic employers and no trusted childminders affected some parents' working lives in a negative way. Some parents felt they had to make unsatisfactory compromises and /or felt they had lost opportunities of a working life or change in career. Difficulties with finding suitable childcare or not trusting others to give the care limited opportunities for parents to socialise with friends or have time away from home with a partner. A major factor contributing to these experiences was the child's frequent severe (often atypical) attacks or chronic poor health. This was related to a high perception of a burden of care and degree of vigilance and

monitoring of the child's health status, which interfered with many aspects of the parents' lives. Even if some social activities could be undertaken, excessive worry and vigilance affected their enjoyment. Thus:

(xiii) The degree of parents' stress and enjoyment in their personal lives is related to the extent to which the child's illness symptoms were believed to require a high level of vigilance.

The experience of family life of various family members had some similarity across the two illness groups. However, siblings participated more in care management in the diabetes group, possibly because care needs were greater. Some siblings in both groups experienced anxiety as a result of witnessing frightening episodes or hearing frightening information. Parents believed this was associated with more protective behaviour towards the sibling. Unusually, parents reported that siblings were at times conflictual, which the parent attributed to more attention being given to the chronically ill child. This behaviour was very difficult to manage, contributing to the parent's stress.

Parenting challenges were also discussed by parents in relation to caring for the chronically ill child. Whilst the parents in both illness groups expressed normal developmentally-related parenting goals, there were added dimensions to these goals because of the illness, including additional demands in protecting the child from undue stress. For the younger children in both groups, parents wished to offer an appropriate level of discipline and setting of boundaries, but sometimes were unsure whether the child's behaviour was related to illness symptoms or just 'normal' misbehaviour. This made this parenting task difficult. Parents also wished to offer older children developmentally-appropriate social opportunities and more independence, but also tended to worry about health risks. This point was raised earlier in relation to the child's social life, with a decision making process about dilemmas. Parenting adolescents was sometimes reported as particularly challenging and stressful, whilst parents tried to find a balance between protection and independence needs. This can be summarised by the following proposition:

(xiv) Parenting children with a chronic illness is particularly challenging at specific times of the child's development. Parents need to make difficult interpretations about the meaning of certain child behaviours, and balance risks against benefits for child development. Whatever parent decision is made, anxiety and guilt may be felt at not making a different choice.

The last part of Objective 4 relates to the impact of the child's illness on family life. Most parents found that where their family 'pulled together', this helped everyone in the family cope better. However there were variations in the interpretation of this ethos. For example, one interpretation is that this means all family members should show empathy with the chronically ill child by having the same privations or experiencing (at least once) the same unpleasant treatment (i.e. injections, blood glucose test in the diabetes group). Privations (e.g. siblings not being allowed sweets) however led to some sibling resentment. Also, the whole family's strong focus on the child's illness led in some families for some members' needs to be overlooked or apparently inadequately considered. For example, some mothers reported their belief that this had contributed to the break-up of the relationship with their partner. Another aspect of this ethos in some families was that the mother and father should share the treatment management; although this was seen positively by most parents, some found it a source of disagreement, although usually temporary. Others divided parenting and household responsibilities differently. Where roles and responsibilities were negotiated (rather than just assumed), most parents reported that this worked well; however, respondents did not always believe that their partner could fully empathise with the stress associated with the treatment burden. In families where the responsibilities were assumed and not negotiated (i.e. it's the mother's job), such feelings of the partner 'not understanding' were sometimes very strong. Similarly, a 'pulling together' ethos of the extended family was more supportive to the core family than a 'detached' ethos. Furthermore, families feel more encouraged to 'pull together' if the burden is not too great and illness outcomes improve. This leads to the proposition that:

(xv) Parents feel supported best where there is a 'pulling together' family ethos, provided that roles are negotiated, and the focus on the ill child is not to the detriment of the needs of other family members. The 'pulling together' ethos is more likely to be sustained if the treatment burden is not too great and the outcomes for child health are good.

Objective 5: Ask questions about the data to explain similarities and differences in parental coping and adjustment, and how and why this changes.

Objectives 7: Examine the psychological concept of adjustment and discuss its meaning in relation to parents of children with Type 1 diabetes and asthma.

Objective 8: Identify which parent behaviours may be reflective of better or less good adjustment, and any predictors of adjustment.

Objective 5 is the process through which Objectives 7 and 8 were achieved. Through asking questions and reviewing the objectives and theoretical propositions, it became apparent that four over-arching themes were threaded throughout these theoretical propositions. These are:

OVER-ARCHING THEME 1: The experience of adjustment

OVER-ARCHING THEME 2: The significance of illness features that affect coping with the illness and with parenting tasks

OVER-ARCHING THEME 3: Assessing and balancing risks and benefits, deciding priorities

OVER-ARCHING THEME 4: Process and outcomes of interpreting and acting on adverse and positive experiences

The first theme, 'The experience of adjustment' relates to how parents generally judge their own and family members' coping and efficacy, and factors that they consider to positively or negatively influence coping and efficacy. The second theme, 'The significance of illness features that affect coping with the illness and with parenting tasks' is related to this, but its reference to coping in specific contexts of illness management and parenting helps to highlight central areas of parents' experience that influence their adjustment. Over-arching theme three, 'Assessing and balancing risks and benefits, deciding priorities' is reflected in some of the theoretical propositions that refer to parents' need to make difficult judgements in illness management, parenting and other situations; the emotional consequences of their decisions can affect adjustment in these areas.

Over-arching theme four is a central one, in that it describes the process through which parents interpret and act in various situations. These include searching for, or trying to understand causes, and making attributions. Parents judge whether causes are external, internal, predictable or controllable. On the basis of these judgements, they decide whether to act, and if so, the extent to which they believe that any actions they take will be effective. When parents observe the consequences, they judge whether they are positive or negative. This affects their beliefs and feelings relating to the experience and also may affect future outcomes that are relevant for adjustment.

These four themes have been helpful in synthesising and organising the elements within this study that are relevant for parent adjustment. They provide a useful framework within which

the theoretical propositions, schematic diagrams and key insights can be mapped. This process is useful in helping to increase the coherence of the developing theory. Appendices 8.1-8.4 on pages 200-207 show how these four themes (and related concepts) have offered further coherence to the elements of this study that will underpin the new theory development. This will help in the construction of the theoretical model that will be presented and discussed later in this Chapter.

8.3 PRESENTATION AND DISCUSSION OF PROPOSED THEORETICAL MODEL

The model presented later in this section reflects that adjustment is a dynamic process, changing according to differing and new situations, growth and development of the child, changing illness experience and other life events. It is important for a model to be able to incorporate individual differences in adjustment, as the data showed that parents who essentially faced similar experiences often interpreted and responded to them differently.

Adjustment of parents is influenced by their expectations and goals, the nature of their experience, their interpretations of these experiences, coping resources and actions, and their evaluation of outcomes. Whilst parents' experiences of adjustment involve a degree of 'uniqueness', there are also patterns of commonality resulting from shared experiences within health, social and cultural contexts. The four core components of this model (Goals, Events, Processes and Outcomes) reflect the areas where considerations and assessments for individual parents can be made, and each of the first three components contribute to the last one, i.e. 'Outcomes'.

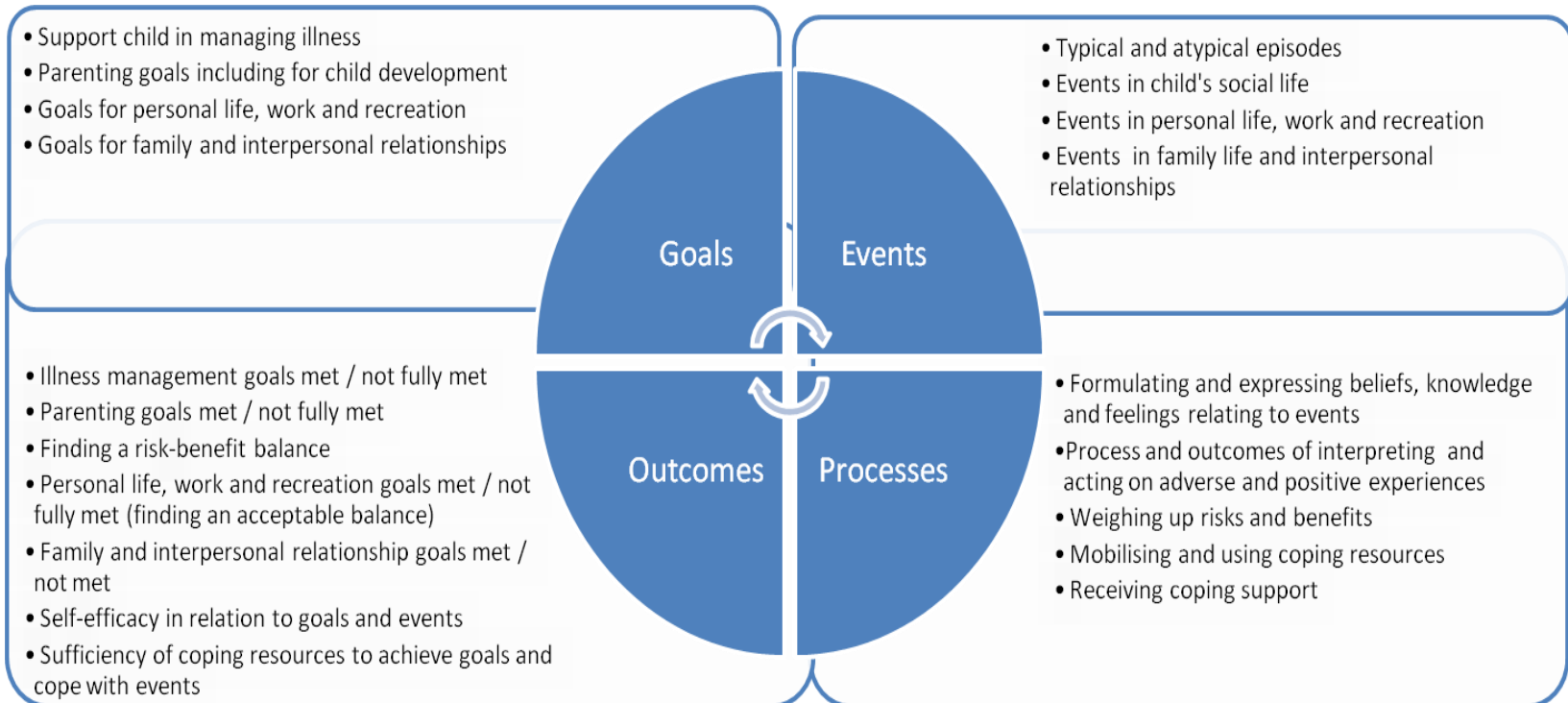
Goals reflect those that parents talked about in relation to managing the illness, parenting and their personal and family life. Goals influence adjustment because if a parent, for example, believes that as a good parent they should provide opportunities for child independence as part of their development, they would regard the child's social restrictions as a serious concern (theoretical proposition ii). It has been found in this study that where parents feel they are not able to attain a goal such as this which is very important to them, they are often deeply distressed. If they are unable to resolve this due to their own actions, this leads to low self-efficacy and anxiety. However, if different parents place less value on this goal, the consequences for adjustment would be less significant.

Events are an essential component of the model because it was found that these vary significantly in nature for different parents and at different points in time. Of particular significance were atypical illness episodes which parents might not have predicted, and for which they were ill prepared. Other events included experiences in the child's social life, where they faced particular challenges (such as participating in active sports). Experiences of a child's non-adherence or challenging behaviour are also included here. Events in relation to the parents' personal or working life (such as employer insensitivity or lack of understanding) and family life (such as sibling responses) are other examples.

Processes have been shown in detail in Appendices 8.1-8.4, particularly relating to, 'Process and outcomes of interpreting and acting on adverse and positive experiences' as well as 'Assessing and balancing risks and benefits'. Again, this important component is reflected strongly in the findings of this study.

The last component, '*Outcomes*' again varies with individuals, and has much to do with how parents respond to events and are able to mobilise and use coping resources. The key areas of significance for adjustment seem to be about whether parents feel their goals have been met and on whether they believe they responded effectively in both everyday and unpredicted situations. Following the presentation of this model (overleaf), further evidence will be shown of how the model relates to the theoretical propositions.

THEORETICAL MODEL: ADJUSTMENT OF PARENTS OF CHILDREN WITH ASTHMA OR DIABETES



8.4 DISCUSSION OF THE THEORETICAL MODEL WITH REFERENCE TO EXISTING LITERATURE

Existing literature will be considered in relation to the four components of the theoretical model identified in this Chapter:

Goals

Although none of the research on parent adjustment made reference to goals as an element of the adjustment process, some of the qualitative studies discussed parents' reports of their goals of gaining competence in managing children's treatment (Hatton et al, 1995; Sullivan-Bolyai, 2006; Wennick and Hallström, 2006). Also, Taanila et al.(1999), in their study on QoL of parents whose child had a recent diagnosis of an intellectual, physical disability or diabetes, reported that parents discussed the importance of a number of aspects of their lives. Parents varied in their views about how important to them were work, social activity and leisure time since the child's diagnosis.

Although research in this area is very sparse with regard to parents of children with a chronic illness, it is reflective of a concept used in sociocultural theory, termed 'emergent goals' (Saxe, 1991). One of a set of concepts discussed by Saxe, it refers to how goals emerge from everyday actions and in interaction with others. Although the concept is widely used in sociocultural theories, it has not yet been incorporated into research on parents' adjustment to having a child with a chronic illness.

Events

The time of diagnosis

The findings from the current study about the experiences of parents of children with diabetes around the time of diagnosis were also found by some of the qualitative research reported in Chapter 2. For example, Wennick and Hallström (2006) carried out a qualitative study in Sweden investigating the lived experiences of families of children where the child had been diagnosed with Type 1 diabetes within the last three months. They reported findings that mirrored almost exactly those of the current study in terms of the parents' experiences and feelings at the time of diagnosis, sibling responses, family changes of routine, worries about blood glucose control, effects on the child's and family's social life, and feelings of lack of confidence in the school's ability to manage the child's treatment.

Similar additional findings reported in the non-categorical qualitative study by Gannoni and Shute (2010), discussed in Chapter 2 were found in the current study also, in particular coping by trying to understand the meaning of the illness, stress-processing, seeking social support, and expressing concerns about the future. Additionally, in common with the current study, Lowes et al. (2005) reported that parents felt shock and grief at the time of their child being diagnosed with diabetes, and that this required having to make significant transitions.

As highlighted in Chapter 2, no qualitative research was identified that investigated the experiences of parents of asthmatic children at the time of diagnosis.

Times of transition

A time of transition has been recognised in some literature as when adolescents start having more independence in care management, and has been considered in the context of needs for changes to the parent-child dyadic relationship. It has been recognised that this time period can be challenging for adolescents and parents alike, and is often characterised by conflict, as noted in parent-adolescent dyads where the adolescent has diabetes (Borrow, 1985; Weinger et al, 2001; Berg et al., 2007). For example, in focus group discussions with diabetic adolescents, Weinger et al. (2001) reported that adolescents explained the sources of a number of conflicts, including differing priorities with the parent (e.g. adolescent focuses on present, and parent on future risks).

In another qualitative study, Mellin et al. (2004) explored parents' perceptions of how Type 1 diabetes affected their relationship with their adolescent daughters. Their findings concurred with those of the present study; parents expressed worries about letting go of the illness management control, but also viewed positively the responsibility shown by the adolescent. The studies in this area have not however considered this conflict in the context of parenting goals, or explored the parents' perspective in any detail.

Similarly, Marshall et al. (2009), in her qualitative study with parents of children with diabetes, identified 'transition' as a theme arising from interviews. Times of transition were discussed in relation to illness management, such as when the child was becoming developmentally ready to take more responsibility for self-care.

No similar studies were found in relation to times of transition of adolescents with asthma, with regard to the parents' experience of adjustment.

Typical and atypical episodes

No research was found that specifically investigated parents' experiences during typical and atypical episodes in their child's illness history. The few phenomenological studies involving parents of children with diabetes have focused on parents' experiences in general, although sometimes at particular time periods such as around the time of diagnosis. However, the study by Wennick and Hallström (2006) referred to above reported that parents of recently-diagnosed diabetic children felt that when in new situations and contexts, they needed to learn again how to manage and respond effectively. This is very close to the concept in this study of 'atypical' episodes being a particular stimulus for new learning; however, the present study also identified how parents felt about these experiences and responded to them. This finding reinforced the proposal that adjustment is dynamic, and changes with events and experiences.

Although a qualitative study by Bowes et al. (2008) was about chronic sorrow in parents of children with diabetes, their findings are of relevance here. They reported that parents frequently re-experienced an upsurge of grief at critical points in their child's development or during re-hospitalisation. Although they did not report parents' experiences during these episodes or explore the significance in detail, these findings reinforce the finding that the nature of episodes can be important for parents' adjustment.

Similarly, although investigating the experiences of parents of children with developmental, learning disabilities and life-limiting conditions, Ajesh et al. (2006) found that insensitive and unsupportive doctors encountered within acute medical situations were reported by parents to be associated with a re-emergence of their grief. This phenomenological study provides some support to the proposition that features of episodes (including being supported by knowledgeable and respectful health practitioners) are important for adjustment.

With regard to the parents of children with asthma, some cross-sectional research such as Gustafsson et al. (2002) did report some features found in some typical episodes of the current study, such as parents' physical and psychological exhaustion and/or sleep problems, helplessness, and feelings of heavy responsibility. Also, some of the qualitative studies with parents of children with diabetes reported some features associated with typical episodes relating to care management, such as feeling that they needed to always be vigilant and that the treatment was burdensome (Hatton et al., 1995; Sullivan-Bolyai et al., 2003; Marshall et al., 2009; Edmonds-Myles, 2010), and that they had periods of feeling incompetent in managing care (Hatton et al., 1995; Sullivan-Bolyai et al., 2003; Wennick and Hallström,

2006). All of these experiences were reported by parents in the current study as significant concerns that impacted on their adjustment.

Processes

Interpreting and acting on experiences – parents of children with diabetes

Some of the theoretical literature on cognitive appraisal has been applied to adjustment in chronic illness. An aspect of cognitive appraisal is ‘attributional style’ or ‘explanatory style’ (Abramson et al., 1989, cited in Carpentier et al., 2006). This supports the finding from the current study that parents looked for causes to try to explain events and outcomes. The high degree of uncertainty and lack of parents’ understanding of new situations is likely to be a stimulus for this process. According to Abramson et al., (1989, cited in Carpentier et al., 2006), research on adjustment of chronic illness has shown that in unknown or ambiguous conditions (such as illness uncertainty), people look for causal explanations to try to explain uncontrollable outcomes. Unfortunately, these explanations are not accurate and focused on a specific cause. Individuals then tend to generalise these explanations to other non illness-related factors, and this can negatively influence an individual’s adjustment.

This aspect of cognitive appraisal has been researched in parents of children with a chronic illness. Holm et al. (2008) investigated how uncertainty about illness outcomes was related to psychological symptoms of mothers and fathers with a range of chronic health conditions. Mothers of chronically ill children who had experienced more illness-related uncertainty had more psychological and physical symptoms than did control mothers, although fathers were unaffected by illness-related uncertainty. These results, and related theory could contribute to explaining the finding in the present study that frequent atypical episodes (such as unpredicted asthma attacks) was associated with parental anxiety and worry about future such events.

In another study, illness uncertainty, and its relationship to attributional style and psychological distress was investigated by Carpentier et al. (2006). Illness uncertainty predicted psychological distress over time in parents of children with type 1 diabetes. This could be one reason why parents described their search for causes in atypical situations (i.e. ones that were not predicted and with uncertain outcomes), and this evidence suggests that finding an accurate cause could be beneficial for adjustment. Self-blame (negative self-focused attributions) was also found by Carpentier et al (2006) to be associated with parenting stress in diabetes and in the sample of parents of chronically ill children as a whole. Again,

in the current study, this was reported by some parents with regard to atypical episodes, particularly if they felt it was due to their own neglect.

Whilst ‘weighing risks and benefits’ was not identified within existing literature, a similar concept was identified, referred to as ‘vulnerability’. Using self-report measures for the child (social adjustment) and parent (perceptions of child vulnerability), Anthony et al. (2003) found that parents viewed their child (with a chronic rheumatology or pulmonary disease) as being more vulnerable where the child had increased social anxiety. This was the case even when controlling for child age and illness severity. However, it’s not clear whether the mothers’ possible over-protectiveness contributed to social anxiety, or the reverse. These authors recommend that assessments should be undertaken to assess parents’ beliefs and parenting practices, as well as child adjustment. Another study made reference to something similar to ‘weighing risks and benefits’, conceptualised in the diabetes management context as ‘being willing not to be a perfectionist’ (Mellin et al. 2004) . Whilst both of these concepts incorporate the idea of risk, there is no mention in the literature about balancing risks against benefits.

Outcomes

Negative outcomes

As discussed in Chapter 2, children with chronic illnesses and their parents are at increased risk of poor adjustment. In the present study, a number of less adaptive sets of behaviours were reported by parents, including excessive monitoring of health state. In the current study, sometimes this was motivated by an attempt in the parents of diabetic children to avoid ‘hypos’.

Monaghan et al. (2009) investigated the incidence of nocturnal blood glucose monitoring. They identified children’s illness characteristics and parents’ fear of hypoglycaemia, anxiety and parenting stress was associated with night blood glucose monitoring (NBGM). Frequency of NBGM was positively associated with increased parent-reported anxiety and parenting stress.

Streisand et al. (2005) also described this type of behaviour in this population of parents. They hypothesised, based on prior research findings, that parenting stress in relation to illness management would relate to parents’ self-efficacy beliefs, level of responsibility and fear of hypoglycaemia attacks. Streisand et al. found that fear of attacks (reflected in excessive blood

glucose monitoring) as well as the other two variables accounted for about one third of parenting stress. Lower self-efficacy was also related to greater parenting stress.

These findings coincide with those of the current study, where some parents described a high level of monitoring; however, this was generally following an 'atypical' severe 'hypo'. So whilst the research by Streisand et al. has face validity, the present study findings provide an explanation for the context and stimulus of such behaviours. Also, it shows that such stress may be context-linked (i.e. following a recent unexpected episode) rather than necessarily an enduring parental stress.

Another negative outcome identified in the literature related to adolescent-parent conflict (referred to earlier) in relation to illness management. Adolescents sometimes felt their parents interfered too much in the illness management, which was reported as a source of worry and some ambivalence for parents in the current study. Harris et al. (2008) developed a measure of 'miscarried helping', to ensure the child's adequate self-care. The measure, when validated within their study, showed that 'miscarried helping' correlated positively with parent-child conflict and parent nonsupport of treatment, also inversely with both mother and child reported adjustment to diabetes and youth-reported adherence to treatment.

This type of behaviour was also reported by some parents in the current study. However, this tended to be where the parent had good reason to worry about the adolescents' responsibility with regard to treatment management. Parents discussed their adolescent's irritation about 'nagging', but parents 'nagged' because the adolescent was non-adherent. Other adolescents were happy to have 'reminders' from their parent, having sometimes forgotten aspects of their treatment.

Hafetz and Miller (2010), in their qualitative study of adolescents with Type 1 diabetes and their parents in treatment monitoring situations, found that parents reminded adolescents about treatments and tracked indicators of treatment adherence. Adolescents reacted with a range of responses, from acceptance to irritation, sometimes withholding information. This was also found in the present study, but has perhaps offered further insights into why adolescents react differently.

No studies were found that related to similar aspects of care of adolescents with asthma. This could be because the treatment is less complex, and older adolescents would be unlikely to need a great deal of support from parents. In fact, a number of adolescents in the current study took more responsibility than their parents, for example, telling them when they needed

to order more medication. This reinforces the point that illness-specific features can be very important for adjustment.

Positive outcomes

Coping strategies

Few studies reported positive aspects of adjustment by parents of children with diabetes, although a notable exception was one by Mellin et al. (2004). However, these did not include those of the present study, such as feeling positive about effective treatment management or prevention of attacks, being able to control the risk of complications and trying not let the illness and treatment run their lives. Neither this study nor others made reference to how parents felt positive if their goals to provide 'normal' experiences and development opportunities for their child were met. Helping the child to achieve personal goals or to be an effective parent and achieve goals to meet personal and family needs was found in this study to be an important outcome of adjustment.

A few other researchers reported different positive coping strategies used by parents. For example, Horton and Wallander (2001) found that for mothers of children with cerebral palsy, spina bifida or diabetes, hope and social support was negatively correlated with maternal distress. In the current study, parents reported that both of these strategies were helpful, such as positive reconstruction (e.g. 'It could have been cancer'), and seeking and receiving support from the extended family and the diabetes or asthma medical / nursing team.

Other coping strategies were reported by Kratz et al. (2009) in their qualitative study assessing an educational intervention to support parents of children with a chronic illness. Strategies that helped parents to cope were 'being prepared', connecting with peers, becoming an advocate, developing partnerships between parent and child, and caring for themselves. All these strategies were also reported in the current study, which has enabled the context of applying these strategies to be explored.

The study by Mellin et al. (2004), referred to earlier, identified that 'reducing worries' was an important coping strategy, particularly thinking positively (having faith things will work out), checking the child at night, and the parent changing their lifestyle (reducing to part-time). Although these authors saw these as positive coping strategies, some parents in the current study generally saw the latter two as unavoidable, i.e. not chosen. For some parents, these

requirements were viewed as disappointing rather than deliberately chosen to 'reduce worries'.

Another finding of Mellin et al. was that parents of children with diabetes viewed positively that they were eating more healthily, had less sugar, and were able to stop smoking. Again, whilst some parents in the current study had similar views, others did not see these lifestyle changes in such a positive way; for example, one father said he was eating the food he liked whilst at work rather than at home, with the explanation, 'I'm not diabetic'. Mellin et al. also reported that parents viewed positively how their child had grown in maturity. Whilst this was also found with some parents, others viewed this less positively, feeling that their child had to grow up too quickly, losing their normal childhood. These points highlight that it is important to be aware that different parents may view the same event or experience as either positive or negative, which has implications for adjustment. For example, the father who was disgruntled about having to eat the food he liked at work would adjust less well than a parent who embraced the idea of having a 'healthy' diet. This reinforces the value of the theoretical model of this Chapter to be aware of the importance of parents' goals.

8.5 REVIEW OF THE STRENGTHS AND LIMITATIONS OF THE STUDY

The findings of this study have offered new insights in a range of areas with regard to the adjustment of parents of children with a chronic illness, and in particular those whose child has asthma or Type 1 diabetes. No other qualitative research study has previously been conducted on this scale that explored parents' perspectives of the many facets of parents' personal lives, the impact on them of the child's illness experience and on their family life.

In Chapter 1, it was explained that there is debate about whether it is beneficial to take a categorical or non-categorical approach to investigating adjustment to a chronic illness. This study has shown that whilst there are common aspects to the experiences of parents of children with a chronic illness, there are also differences that are important to recognise. For example, illness-specific features such as whether it is common to have unpredictable attacks or symptoms, whether treatment is unpleasant and / or complex, the consequence of omitting treatment either occasionally or regularly, whether the consequences of omissions of treatment are severe and whether the illness is expected to decline, vary in severity over time, or shorten lifespan all impact on children's and parents' ability to manage the illness and adjust to this experience. Therefore, it is recommended that the advice of Lavigne and Faier-

Routman (1992) be followed; they argue that researchers should examine both common and illness-specific factors when investigating adjustment in the chronic illness experience.

This study is also unique in considering adjustment of parents from the perspective of the child's developmental stage. Whilst non-adherence and conflict have been investigated in adolescents with chronic illness, the perspective of parents, and in particular parenting goals have not been considered. The dilemmas faced by parents at different stages of their child's development in terms of balancing parenting goals for the child's development and protecting them from risks is not a concept that has so far been presented.

Finally, although a few longitudinal studies have been undertaken on the parents' experience over time, most of these are of short duration (about 1 year), and do not necessarily investigate the parents' adjustment over key phases for adjustment (i.e. diagnosis, the period after initial adjustment, and during adolescence when parents are thinking about their child launching out into the world). Although this study was not longitudinal, parents reflected on their experiences throughout the illness course and described their concerns and thoughts about the future; also there was a cross-section of child age ranges in this study, which enabled adjustment in relation to time course to be considered to some extent. Longitudinal studies however are needed to further elucidate these experiences over time, and how they impact on adjustment.

The study has good credibility, as shown by the mirroring of many of the results from this study in previous research. A detailed and consistent approach was taken to developing and refining codes, coding and indexing data and presenting results. At each step, supervisors of this study were involved in verifying initial codes developed as reflective of the data, offering further insights into the meaning of the data, and discussing possible interpretations of the data. This has contributed to the study's credibility and rigour. During the interview process and whilst transcribing the data, notes were made of how questions were asked and how parents' verbal and non-verbal communications were interpreted. This reflexivity is important in order to ensure that the parents' perspectives are truly reflected in the data, and that prejudgements or assumptions are not made by the researcher. It was felt that on the whole, this was achieved in the interviews, although it was felt at times that being a children's nurse by background influenced some comments and questions posed. It also influenced some of the parents' questions, for example about treatment. Indeed a therapeutic meaning was given to the interviews by some parents. For example, one parent approached me at clinic some time after the interview to tell me how the interview was helpful and therapeutic

for her. However, there is no reason to believe that this was detrimental to the credibility of the data.

The study had some limitations with reference to the ideal for a grounded theory approach. Purposive rather than theoretical sampling was undertaken; however this was unavoidable due to the difficulties in recruiting sufficient participants. Had theoretical sampling been used, some queries that arose during the data analysis might have been pursued in more detail. For example, only one couple in the diabetic group had a child diagnosed within the last year. The experience of these parents was different to those of some others, and had it been possible to recruit more parents of recently-diagnosed children, this finding could have been investigated further.

The size of this sample was good for a qualitative study, and included parents from a wide range of backgrounds, family situations, family size, and from urban and rural homes. However, most participants were from the same cultural group, although two parents in the asthma group were from families with different cultural backgrounds (Afro-Caribbean, South American). It would be beneficial to investigate how parents' cultural backgrounds (for example, influencing different parenting styles, family support expectations) might impact on their adjustment.

The interview approach of undertaking joint interviews with mothers and fathers together was beneficial, in that it was not only possible to learn where perspectives were similar or sometimes different, but of the dyadic relationship between the parents. On the other hand, it might have been valuable to have also interviewed the parents separately, as they might not have said the same things in the two contexts. This suggestion is reinforced by some of the qualitative studies reviewed in this thesis, showing that when the experiences of fathers was investigated separately, some different findings were shown than when the sample was only mothers or both mothers and fathers. Future researchers may wish to consider interviewing parents separately and then together to investigate this possibility further.

8.6 RECOMMENDATIONS FOR FUTURE RESEARCH AND PRACTICE

As discussed above, there would be value in future researchers investigating further the nature of child developmentally-related changes in parents' experience, and its impact on adjustment. Related to this, researchers could investigate further the experiences relating to the parenting role in the context of the child's chronic illness. Further investigation of

experience of fathers, and the use of longitudinal studies over the full illness course would also be beneficial.

The theoretical model developed in this study could be a useful framework for future research and clinical practice. This would offer a more coherent framework for a field of research that is very disparate in objectives and theoretical orientation. In clinical practice, the model could be used as a basis for exploring parents' adjustment. By considering parents' goals, a more individualised, holistic approach may be brought to the child and family assessment. Practitioners' discussion of parents experiences and concerns around events will offer insights into particular stressors (for example, fearful or unexpected recent episodes), as these experiences may require sensitive and specific support in order to meet parents' needs. Having an awareness of processes used by parents to interpret and respond to their experiences (particularly looking for causes) is important for practitioners to consider, as they may be more able to offer targeted help (for example, information about why an attack might have occurred, and how it could be prevented in future). Finally, it is important to consider outcomes for parents, not just in terms of whether they are managing to support their child's health, but also in relation to supporting the development and use of coping resources and assessing whether the parents' goals are being met in other aspects of their lives. It is a model that can be used by the multi-professional health and social care team, which could be beneficial for integrated care of the child and family.

8.7 CONCLUSION

The long journey to reach the new understanding on this topic has been an exciting and enlightening one. A better appreciation of the experiences of parents of children with a chronic illness, in particular asthma or diabetes has been gained. Of particular value in terms of contribution to the body of knowledge will be the theoretical model and associated theoretical propositions. The schematic diagrams will also be useful for researchers and practitioners who may find these beneficial when investigating further the significance of certain themes or situations. It will be important to disseminate these findings widely in order to stimulate the generation of new research on this under-researched topic and to benefit the children and families to whom this study relates.

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OXFORD BROOKES UNIVERSITY

**Adjustment of Parents
of Children with Asthma or Type 1 Diabetes**

APPENDICES

to a thesis submitted
in part fulfilment of the requirements for the award of a PhD

by

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December, 2010

APPENDICES

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29 June 2004

Mrs Sandra Oldfield

Dear Mrs Oldfield

Full title of study: Coping and Adjustment of Parents of Children with a Chronic Illness
REC reference number: 04/Q1606/26
Protocol number: n/a

Thank you for your letter of 18 June 2004, responding to the Committee's request for further information on the above research.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation.

The favourable opinion applies to the following research site:

Site:

Principal Investigator: Mrs Sandra Oldfield

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type: Application
Version: n/a
Dated: 23/04/2004
Date Received: 26/04/2004

Document Type: Investigator CV
Version: Sandra Oldfield
Dated: 26/04/2004

Date Received: 26/04/2004

Document Type: Investigator CV

Version: Terezinha Nunes

Dated: 26/04/2004

Date Received: 26/04/2004

Document Type: Interview Schedules/Topic Guides

Version: Parents v2

Dated: 18/06/2004

Date Received: 18/06/2004

Document Type: Interview Schedules/Topic Guides

Version: Professionals v2

Dated: 18/06/2004

Date Received: 18/06/2004

Document Type: Letters of Invitation to Participants

Version: Professionals v2

Dated: 18/06/2004

Date Received: 18/06/2004

Document Type: Letters of Invitation to Participants

Version: Parents

Dated: 18/06/2004

Date Received: 18/06/2004

Document Type: Participant Information Sheet

Version: Parents v2

Dated: 18/06/2004

Date Received: 18/06/2004

Document Type: Participant Information Sheet

Version: Professionals v2

Dated: 18/06/2004

Date Received: 18/06/2004

Document Type: Participant Consent Form

Version: Professionals v2

Dated: 18/06/2004

Date Received: 18/06/2004

Document Type: Participant Consent Form

Version: Parents v2

Dated: 18/06/2004

Date Received: 18/06/2004

Document Type: Response to Request for Further Information

Version:

Dated: 18/06/2004

Date Received: 18/06/2004

Document Type: Other

Version: Guidelines for assent v2

Dated: 18/06/2004

Date Received: 18/06/2004

Document Type: Other

Version: Assent Form v2
Dated: 18/06/2004
Date Received: 18/06/2004

Document Type: Other
Version: Covering Letter to , R&D Administrator
Dated: 26/04/2004
Date Received: 26/04/2004

Document Type: Other
Version: Covering Letter to , R&D Administrator
Dated: 22/04/2004
Date Received: 26/04/2004

Document Type: Other
Version: Oxford Brookes Ethics Approval
Dated: 04/02/2004
Date Received: 26/04/2004

Document Type: Other
Version: Reply Slip - Parents v2
Dated: 18/06/2004
Date Received: 18/06/2004

Management approval

The study may not commence until final management approval has been confirmed by the organisation hosting the research.

All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant host organisation before commencing any research procedures. Where a substantive contract is not held with the host organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Notification of other bodies

We shall notify the research sponsor – NHS Trust that the study has a favourable ethical opinion.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

REC reference number: 04/Q1606/26 Please quote this number on all correspondence

Yours sincerely,

Chairman

Enclosures Standard approval conditions

7 September 2005

Ms Sandra Oldfield

Dear Ms Oldfield

Study title: Coping and adjustment of parents in children with a chronic illness
REC reference: 04/Q1606/26

Amendment number: 1
Amendment date: 19 August 2005

The above amendment was reviewed at the meeting of the Sub-Committee of the Research Ethics Committee held on 7 September 2005.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Notice of Substantial Amendment 19 August 2005

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Research governance approval

All investigators and research collaborators in the NHS should notify the R&D Department for the relevant NHS care organisation of this amendment and check whether it affects research governance approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

REC reference number: 04/Q1606/26 Please quote this number on all correspondence
--

Yours sincerely

Committee Co-ordinator

Copy to: R&D Dept,

Enclosures *List of names and professions of members who were present at the meeting*



NHS Trust

From the Medical Director

Mrs Sandra Oldfield

Dear Mrs Oldfield

11 May 2004

**Re: 4508 – Coping and adjustment of parents of children with a chronic illness
04/Q606/26**

I can confirm that the Oxford Radcliffe Hospitals NHS Trust will provide management approval for the above study, as described in your application to the Research Ethics Committee. This confirmation is dependent on the formal approval of the Research Ethics Committee.

This letter also confirms that indemnity will be provided by the Trust for the above study according to the information you have provided within the application form. This confirmation is also subject to the formal approval of the Research Ethics Committee and on the understanding that you have a contract of employment with this Trust.

Trust management approval and indemnity is ongoing and dependent upon completion of satisfactory annual reports when requested by the Trust

I wish you every success with the study.

Yours sincerely,

Medical Director

CC Ethics Administrator

N.B.: There were two versions of this parent letter. The text in bold was either asthma or diabetes, depending on the intended recipient(s).

[address] xxxx

e-mail: xxxx

tel: xxxx

Dear parent / guardian,

Re: Research Study

I would like to invite you to take part in a research study. I am a children's nurse and Senior Lecturer at Oxford Brookes University, currently undertaking a research degree (PhD). My research is to interview parents such as yourself who have a child with **asthma / diabetes**.

I recognise that having a child with **asthma / diabetes** can be hard, but that many parents find helpful ways of adjusting to it. Although other researchers have found out some information about parents' and their families' experiences, we don't yet know very much about what is helpful or less helpful for them in personally adjusting to these experiences. I would like to find out more about this through interviewing parents, and then use this information to develop a questionnaire. This can then be used for other parents in the future to help identify parents' needs quickly and effectively, and to offer specific, practical help.

Please find enclosed an information sheet about the study. If after reading the information sheet you are interested in taking part in the study, please return the reply slip (at the end of the Information Sheet) to me in the envelope provided, or you can contact me directly.

If you would like to take part, I can contact you directly at your child's next clinic appointment or at another time and place convenient to you.

Thank you for taking the time to consider being a participant in this study.

Yours sincerely,

Sandy Oldfield

(* In this study, the term 'parent' refers to a person undertaking a parenting role for a child, and could include step-parents and foster parents)

N.B.: There were two versions of this information sheet. The text in bold was either asthma or diabetes, depending on the intended recipient(s).



INFORMATION SHEET FOR PARENTS / GUARDIANS

Coping and Adjustment of Parents of Children with **Asthma / Diabetes**

(N.B. The term 'parent' refers to someone fulfilling a parenting role for a child)

What is the purpose of the study?

The purpose of the study is to develop a questionnaire for parents of children with **asthma / diabetes**. Nobody has yet developed a questionnaire like this, which would help nurses and doctors to quickly and accurately find out how parents and their families are adjusting to having a child with **asthma / diabetes**. This information would help them to offer the support that would be most useful to them.

I will collect this information through meeting and interviewing parents. It is important that the questionnaire is based on true information about parents' everyday experiences, and what they have found helpful and less helpful when adjusting to their child's **asthma / diabetes**. I will need to talk to parents who have managed to adjust to their child's **asthma / diabetes** very well, as well as those who may have found this more difficult.

Why have I been selected to possibly participate in this study?

You have been selected as a possible participant in this study because you are a parent, step-parent, adoptive parent or foster parent of a child with **asthma / diabetes**, currently living at the same address as your child.

What do you plan to do, and why are you doing it? How much time will I need to spend on this if I decide to participate?

If you decide to participate in this study, you would be asked to do the following:

You would be asked if you would be willing to be interviewed by a PhD student (Sandy Oldfield) about your experiences of being a parent of a child with **asthma / diabetes**.

If you agreed to participate, the interview would take about an hour, and could take place either at the time of a visit to clinic with your child, or at another time and place of your choice. The interview would be tape recorded (with your permission) to make sure that your responses were accurately recorded.

Nobody except your interviewer would know that it was your voice on the tape, and any information that could identify you personally would be removed afterwards. A second researcher from the study might listen to the tape to make sure that the information recorded on paper was accurate and interpreted correctly.

Once the information from all of the interviews has been collected and analysed, you would be sent a summary of results and also invited to attend a meeting with other parents and health care professionals to discuss the outcomes of the study.

Might my participation in the study be inconvenient or uncomfortable?

The interview would take about an hour. If you wished to be interviewed on a day when you were attending a normal clinic visit, then you might need to come slightly earlier or stay slightly later on that day.

Many people like you find it helpful to talk about personal experiences. However, if you felt at any time that you did not want to talk any more about the subject and you wanted to stop the interview, that would be fine. If you later decided that you wanted to talk some more about this, then I would be happy to refer you to someone who could provide this help.

Are there any possible risks or benefits to me if I decide to participate?

There are no known risks for you if you decide to become involved in this study.

Apart from any immediate benefit that you might experience as a result of talking with someone about your experiences, you are likely to benefit from attending a meeting of all the participants at the end of the study. This would give you a chance to hear how other parents cope with and adjust to their child's illness, perhaps giving you some ideas for yourself. You might also feel positive about the contribution that you would have made to helping parents and health care professionals to more accurately assess the needs of parents like yourself.

How would my privacy and anonymity be maintained?

Any information gained from interviews would be anonymous and confidential. It would not be possible for anyone (other than the person carrying out the interviews) to know who you are.

The people who would be able to see the anonymous information, which could include some of your own words, would be Sandy Oldfield, her research supervisors or assessors and researchers who are specifically interested in this subject. Any information about you would be removed and destroyed before being analysed. When any reports of the study are published, there will be no record of any parents' names or other information that could help to identify them. The information that has been gathered will be stored in a locked filing cabinet in a secure room, or on a password-protected computer. The information will be kept for up to 5 years.

Would I be able to withdraw from the study at any time and for any reason?

Yes, you would be free to withdraw at any time and would not need to give a reason for this. This would not affect your child's health care in any way.

Who may I contact if I have any questions now or on a future occasion?

Please contact Mrs. Sandy Oldfield:

Xxxxxxx

e-mail: xxxxx

If you have any concerns about the study, you may also contact the School Research Ethics Officer, xxxxxxx, in the School of Social Sciences and Law (tel. 01865 483775), or xxxxxxxx, Chair of the University Research Ethics Committee, Oxford Brookes University (tel. 01865 4833758).

Thank you for considering taking part in this study. If you think you might be interested in participating in the study, please complete the slip overleaf, and return it in the envelope provided, to Sandy Oldfield. If you are in hospital with your child at the moment, you can return the slip in the hospital internal post by asking the receptionist or ward clerk to put it into the internal post tray. Otherwise, it may be returned through the normal post.

(PLEASE TURN OVER PAGE)

If either one or two parents would like to consider taking part in this study, please return this slip in the envelope provided, addressed to:

Xxxxxx

e-mail: xxxxxx

tel: xxxxx

Thank you

✂.....

I _____ (name/s)
would like Sandy Oldfield to see me to discuss the study when I come with my
child to their asthma / diabetes clinic appointment at xxxxxxxx.

This appointment will be on _____ (date)
at _____ (time).
(or)

I
_____ (name/s)
would like Sandy Oldfield to arrange another time to meet, and would like
her to contact me. I can be contacted by phone on the following
number _____ or by e-mail at the following
address _____.

I understand that this meeting will give me an opportunity to find out more about
the study and possibly to give my consent to participate.

Signed (parent) _____

Name in block
letters _____

Signed (second parent, if desired) _____

Name in block
letters _____

Child's name in block
letters _____

N.B.: There were two versions of this letter. The text in bold was either asthma or diabetes, depending on the intended recipient(s).



Dear Sir or Madam,

Re: Coping and Adjustment of Parents of Children with **Asthma/Diabetes***

I am a children's nurse and Senior Lecturer at Oxford Brookes University, currently undertaking a research degree (PhD). I aim to develop a questionnaire and other assessments that can help health care staff to identify (or understand) better the needs of parents of children with asthma. Specific assessment tools for this group of parents do not presently exist. I would like to invite you to consider participating in this study. This invitation is being extended to parents, health care professionals and support group leaders as individuals or in their role as team leaders.

Please find enclosed an information sheet about the study. I would be grateful if you would give a few minutes of your time to read through it, and discuss this with your team (if you are a team leader) before considering your participation.

I will be approaching you shortly to discuss if you or your team would be willing to participate in the study. Thank you for taking the time to consider participation in this study.

Yours sincerely,

Sandy Oldfield

(*In this study, the term 'parent' refers to a person undertaking a parenting role for a child and could include step-parents and foster parents)

N.B.: There were two versions of this information sheet. The text in bold was either asthma or diabetes, depending on the intended recipient(s).



INFORMATION SHEET FOR PROFESSIONALS AND TEAM / SUPPORT GROUP LEADERS

Title of the Study: Coping and Adjustment of Parents of Children with **Asthma / Diabetes**

What is the purpose of the study?

The purpose of the study is to find out how parents of children with **asthma / diabetes** respond to the related changes in their life, and what helps to make this a more positive experience for them.

A number of ways will be used to collect this information through meeting and interviewing parents, professionals and support group leaders, and observing team meetings.

The information will then be used to develop questionnaires and observation measures to help parents and health care professionals to assess parents' needs.

Why have I been selected to possibly participate in this study?

You have been selected as a possible participant in this study because you are a health care professional, support group leader or chairperson/leader of a team involved in support of children with **asthma / diabetes** and their families.

What do you plan to do, and why are you doing it? How much time will I need to spend on this if I decide to participate?

If you decide to participate in this study, you would be asked to do one of the following:

- (a) You might be asked if you would be willing to be interviewed by a PhD student (Sandy Oldfield) about your experiences, feelings and thoughts about the responses of children and families with **asthma / diabetes**. This information will be used to help design questionnaires or other paperwork to help assess parents' needs.

If you agreed to participate, the interview would take about an hour, and would take place at a mutually convenient time and place. The interview would be tape recorded (with your permission) to make sure that your responses were accurately recorded.

Nobody except your interviewer would know that it was your voice on the tape, and any information that could identify you personally would be removed afterwards. A second researcher from the study might listen to the tape to make sure that the information recorded on paper was accurate and interpreted correctly.

- (b) If you are not asked for an interview, you might be asked, either as an individual or as a chairperson/leader of a team, if a PhD student (Sandy Oldfield) could observe the process of a team meeting or interactions with a family on a home visit. The purpose of this is to identify important issues for and responses of families of a child with **asthma / diabetes**.

If you are a chairperson / leader of a team, then you would be asked to seek permission from the other members of the team for Sandy to attend and observe the proceedings of the meeting.

You or members of your team would not be asked to do anything other than to agree for Sandy to observe what was going on during the visit or meeting. During the observation episode, she would be taking notes, but these would not contain any information that could identify any participant personally. The visit or team meeting would not be any longer than normal.

Once the information from all of the interviews and observations have finished and been analysed, you would be sent a summary of results and you and your team (if applicable) would be invited to attend a meeting with other participants to discuss the outcomes of the study with the researcher.

Might my or my team's participation in the study be inconvenient or uncomfortable?

If you agreed to an interview:

The interview would take about an hour. Inconvenience would be limited, as this would take place at a time that would be negotiated with you.

If you agreed to a researcher attending a team meeting:

It is possible that you or some team members might feel a little uncomfortable and inclined to behave less naturally if you or they know that an observer is in the room. This is perfectly normal. However, most people don't feel as self-conscious after the first few minutes.

Are there any possible risks or benefits to me if my team / group or I decide to participate?

There are no known risks for you or your team if you decide to become involved in this study.

You may benefit from participating in an interview, which might help you to clarify your own ideas and impressions about parents' needs. You and your team (as applicable) would be invited to a meeting at the end of the study, where you would have an opportunity to find out and discuss the results of the study, which may have relevance for your own practice. You might also feel positive about the contribution that you would have made to helping parents and health care professionals to more accurately assess the needs of parents.

How would privacy and anonymity be maintained?

Any information gained from interviews or observations would be anonymous and confidential. If you are being interviewed, it will not be possible for anyone (other than the person carrying out the interviews) to know who you are. If being observed, only those present at the time would know what happened during the home visit or team meeting.

The other people who would be able to see the anonymous information would be Sandy Oldfield, her research supervisors or assessors and researchers who are specifically interested in this subject. Any information about participants would be removed and destroyed before being analysed. When any reports of the study are published, there will be no record of any participants' names or other information that could help to identify them. The information that has been gathered will be stored in a locked filing cabinet in a secure room, or on a password-protected computer. The information will be kept for up to 5 years.

Would I be able to withdraw from the study at any time and for any reason?

Yes, you would be free to withdraw at any time and would not need to give a reason for this.

Who may I contact if I have any questions now or on a future occasion?

Please contact Sandy Oldfield (PhD student) at xxxxxxxx, by e-mail at xxxxxxxxx or at her work address which is:

xxxxxxxxxx

If you have any concerns about the study, you may also contact the School Research Ethics Officer, xxxxxx, in the School of Social Sciences and Law (tel. 01865 483775), or xxxxxxxxxxxx, Chair of the University Research Ethics Committee, Oxford Brookes University (tel. 01865 4833758).

Thank you for considering taking part in this study. Sandy Oldfield will be contacting you in the near future to discuss if you or your team / group would like to participate in the study.

N.B.: There were two versions of this form for parents. The text in bold was either asthma or diabetes, depending on the intended recipient(s). A similar consent form was used for professionals / support group leader.



[address xxxx]

CONSENT FORM FOR PARENTS / GUARDIANS

Study Title: Coping and Adjustment of Parents of Children with **Asthma / Diabetes**

Before signing this consent form to agree to participate in the study, please indicate that you have read and understood the following:

Have you read the invitation letter? YES NO

Have you read the Information Sheet for Parents / Guardians? YES NO

Have you had an opportunity to ask questions and discuss the study? YES NO

Have you received satisfactory answers to all your questions? YES NO

Who have you spoken to about the study? Mrs. Sandy Oldfield (tick to confirm)

and (add any other names).....

Do you agree to participate in the study, but understand that you are free to withdraw from the study:

- at any time
- without having to give a reason for withdrawing
- and without affecting your future health care? YES NO

If you are being interviewed, do you agree to your words possibly being used as an example of parents' responses? (Note that you will not be identified). YES NO

If you are being interviewed, do you agree to the interview being audio-taped? YES NO

Signature of participant:.....

Name (Block letters):.....

Signature of researcher.....Date:.....

N.B.: There were two versions of this interview schedule. The text in bold was either asthma or diabetes, depending on the intended participant(s).

Name of parent/guardian:

Name of child:



(section above to be detached following assignment of participant number)

Relationship to child (e.g. father, mother, step-mother, etc):

Occupation and work pattern of parent:

Age and gender of child:

Age and gender of any siblings:

Type of chronic illness that the child has:

Time since diagnosis:

INTERVIEW SCHEDULE – PARENT/GUARDIAN – CHILD WITH
ASTHMA / DIABETES

PARENT’S / GUARDIAN’S FEELINGS:

What experiences did you have when your child was first diagnosed?

How did you feel when your child was diagnosed?

How do you generally feel now about your child having **asthma / diabetes**?

Is this typical of how you normally feel?

What do you consider to be your greatest concerns at present and for the future?

How much does your child’s illness affect his or her life? Can you give me some examples?

How much does your child’s illness affect your personal life? How does this make you feel?

How much does your child’s illness affect the way you relate to him/her? How does this make you feel?

When was the last time your child was ill? How did you feel at that time?

FAMILY INTERACTIONS:

Who in your family is involved in managing your child’s **asthma / diabetes**? (For example, partner, grandparents, other children)? Do they take the same approach as you in managing asthma / diabetes?

Do you think that the relationships within your family have changed as a result of your child having this illness? If so, what do you think has led to this change?

(If more than one child) – Do you feel that it's possible to treat your children equally? What do you understand by treating children equally?

Since your child's illness was diagnosed, what would you say were the times when you felt least positive about your family's relationships? Why do you think you felt less positive at these times?

Since your child's illness was diagnosed, what would you say were the times when you felt most positive about your family's relationships? Why do you think you felt most positive at these times?

INTERACTIONS WITH SCHOOL PERSONNEL:

At your child's school, who knows about your child's **asthma / diabetes**?

How have the staff at your school found out about your child's health needs?

How have the teachers and nurses at your child's school responded to your child having **asthma / diabetes**?

Can you give me some examples of things that have happened at school, and how they handled it?

How would you describe your relationships with school personnel when it comes to managing your child's illness?

What would you say were the times when you felt least positive about your relationships with teachers and nurses at school? Why do you think you felt less positive at these times?

What would you say were the times when you felt most positive about your relationships with teachers and nurses at school? Why do you think you felt most positive at these times?

MEDICAL TREATMENT - HOME ENVIRONMENT:

What treatments, tests and/or medications does your child need, and how often are they needed?

Does everyone involved in managing your child's illness have the same understanding of how these work and what they're for?

Does your child have any side effects of their medication?

What symptoms does or could your child experience?

How are these (all of above) managed or prevented at home and by whom?

Prompts:

Who decides when and how special routines should be carried out?

Who actually carries out the routine medical care?

For example, who decides which site to use for injections, or what food to choose?
Who decides when they should do their blood testing and when and what they should eat?

What would you say were the times when you felt least positive about the management of your child's care at home? Why do you think you felt less positive at these times?

Prompt: Did you do anything or change the way you thought about anything that were not particularly helpful in these situations?

What would you say were the times when you felt most positive about the management of your child's care at home? Why do you think you felt most positive at these times?

Prompt: Did you do anything or change the way you thought about anything that particularly helped you in these situations?

MEDICAL TREATMENT: HOSPITAL OR SURGERY ENVIRONMENT

Does your child often have to go to hospital or your local surgery to have treatment?

If they do, why does he/she usually have to go?

How does he/she usually react to going to the hospital or surgery for an assessment or treatment?

How do you usually react to going to the hospital or surgery for your child's assessment or treatment? What do you find helps you or makes you more upset then?

Is your child sometimes upset during an assessment or treatment? What makes them upset?

How do you usually respond if your child is upset?

What would you say were the times when you felt least positive about supporting your child when they have been upset? Why do you think you felt less positive at these times?

Prompt: Did you do anything or change the way you thought about anything that were not particularly helpful in these situations?

What would you say were the times when you felt most positive about supporting your child when they have been upset? Why do you think you felt most positive at these times?

Prompt: Did you do anything or change the way you thought about anything that particularly helped you in these situations?

Name of health care professional or support group leader:



(section above to be detached following assignment of participant number)

Professional group of participant:

INTERVIEW SCHEDULE - PROFESSIONAL OR SUPPORT GROUP LEADER

OBSERVATIONS OF PARENTS:

What kinds of reactions do parents have when their child is first diagnosed?

What kinds of reactions do parents have later on (specify time period)?

In which ways does the child's illness affect parents' lives?

Initially and over time, do parents change the way that they relate to their child? If so, how?

OBSERVATIONS OF FAMILY INTERACTIONS:

How do relationships within families change as a result of their child having this illness?
What do you think leads to these changes?

What difficulties do these families have in their relationships with each other that may be connected to their child's illness?

What strengths do these families have in their relationships with each other that may be connected to their child's illness?

OBSERVATIONS OF INTERACTIONS WITH SCHOOL PERSONNEL:

How have school staff found out about these children's health needs?

How have school staff responded to these children having diabetes / asthma?

How would you describe parents' relationships with school personnel when it comes to managing their child's illness?

OBSERVATIONS OF MEDICAL CARE - HOME ENVIRONMENT:

What treatments, tests and/or medications do these children usually need, and how often are they needed?

Do parents generally know how to cope with symptoms of their child's asthma/diabetes and the correct procedures to follow?

What influences how the families manage the children's symptoms, tests or treatments at home?

What difficulties do these families have in the management of symptoms, tests or medications?

What strengths do these families have in the management of the symptoms, tests or medications?

To what extent do the children take responsibility for the management of their care? What influences this?

Do you think overall that parents are effective in helping their child to control their asthma/diabetes?

OBSERVATIONS OF MEDICAL TREATMENT: HOSPITAL OR CLINIC ENVIRONMENT

How frequently do these children have to be seen by health care professionals?

In a typical year, how often do these children usually come to hospital as booked admissions?as emergency admissions?

What are the most difficult times in the course of their child's illness for parents when they come to hospital? Why?

What responses have you observed in parents when their child is distressed during interventions? What influences their response?

What responses of such parents in hospital indicate to you that they may be distressed or anxious? What tends to help them at these times?

What responses of such parents in hospital indicate to you that they may be relaxed and comfortable? What tends to help them at these times?

Appendix 3.11: Participant Profile – Asthma Group

Parent with asthmatic child	Social class head of household	Parent single or with a partner	Age group and gender of child with chronic illness (Pre-schooler: 2-5 School aged: 5-11 Adolescent: 12-16)	Time since diagnosis	Siblings or step-siblings
Mother of child 'A_1'	4	partner	School aged, male	8 years	Yes
Mother of child 'A_2'	5	partner	Pre-schooler, male	3 years	Yes
Mother of child 'A_3'	3	single	Adolescent, female	14 years	Yes
Mother of child 'A_4'	3	single	Adolescent, female	14 years	Yes
Mother of child 'A_5'	6	single	Adolescent, male	13 1/2 years	Yes
Mother of child 'A_6'	3	single	Adolescent female	11 years	Yes
Mother of child 'A_7'	6	partner	School aged, female	4 1/2 years	Yes
Mother of child 'A_8'	2	partner	Adolescent male	10 years	No
Father of child 'A_8'	2				
Mother of child 'A_9'	1	partner	School aged, male	9 years	Yes
Mother of child 'A_10' (non-clinic)	3	partner	School aged, male	3years	Yes

Parent with asthmatic child	Social class head of household	Parent single or with a partner	Age group and gender of child with chronic illness (Pre-schooler: 2-5 School aged: 5-11 Adolescent: 12-16)	Time since diagnosis	Siblings or step-siblings
Mother of child 'A_11'	6	partner	School aged, male	5 years	Yes
Mother of child 'A_12'	2	partner	School aged, male	4 years	Yes
Mother of child 'A_13'	3	partner	Pre-schooler, male	Not technically diagnosed with asthma, but symptoms from 15 weeks	Yes
Father of child 'A_13'	3				
Mother of child 'A_14' (non-clinic)	3	partner	Adolescent, female	14 years	Yes
Mother of child 'A_15'	3	single	Adolescent, male	11 ½ years	No
Grandmother of child 'A_15'	3	single			
Mother of child 'A_16'	2?	partner	Pre-schooler, male	2 1/2 years	No

Appendix 3.12: Participant Profile – Diabetes Group

Parent with diabetic child	Social class head of household	Parent single or with a partner	Age group and gender of child with chronic illness (Pre-schooler: 2-5 School aged: 5-11 Adolescent: 12-16)	Time since diagnosis	Siblings or step-siblings
Mother of child 'D_1'	3	partner	School aged, male	5 years	Yes
Mother of child 'D_2'	2	partner	School aged, female	5 years	Yes
Mother of child 'D_3'	4	partner	Adolescent, female	2 years	Yes
Mother of child 'D_4'	1	partner	School aged, male	4 years	Yes
Father of child 'D_4'	1				
Mother of child 'D_5'	4	partner	School aged, male	8 years	Yes
Father of child 'D_5'	4				
Mother of child 'D_6'	2	partner	School aged, female	6 years	Yes
Mother of child 'D_7'	6	single	Adolescent, male	6 years	Yes
Mother of child 'D_8'	5	partner	Adolescent, female	2 ½ years	Yes
Father of child 'D_8'	5	partner			

Parent with diabetic child	Social class head of household	Parent single or with a partner	Age group and gender of child with chronic illness (Pre-schooler: 2-5 School aged: 5-11 Adolescent: 12-16	Time since diagnosis	Siblings or step-siblings
Mother of child 'D_9'	4	single	Adolescent, female	8 years	No
Mother of child 'D_10'	2	partner	Adolescent, male	5 years	Yes
Mother of child 'D_11'	1	partner	Adolescent, male	12 years	Yes
Mother of child 'D_12'	3	partner	School aged, female	5 years 10 months	Yes
Father of child 'D_12'	3				
Mother of child 'D_13'	4	partner	Adolescent, female	1 year	Yes
Father of child 'D_13'	4				
Mother of child 'D_14'	3	partner	Adolescent, female	3 ½ years	Yes
Father of child 'D_14'	3				
Mother of child 'D_15'	7	single	School aged, male	5 years	Yes
Mother of child 'D_16'	3?	partner	Adolescent, male	3 years	Yes

APPENDIX 4.1: ASTHMA GROUP: Individuality of response: Behaviour or emotion
All children (aged 2 – 16)

(N.B. Behaviour or emotions are either current or experienced in the past)

Age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	1A_5	1A_6
Behaviour or emotion component																
<i>Externalising behaviour (non-hospital)</i>																
Being 'stropky', stubborn or argumentative			√			√								√		
Shows anger, lashing out		√														
Gets cross/ frustrated if feels over-protected and / or can't do things				√												
Denies being unwell						√										
Can be manipulative / tend to 'play up' to other people														√		
Conflict with parents at mealtimes								√								
Likes to be 'wacky' in appearance						√										
<i>Internalising behaviour (non-hospital)</i>																
Tendency to prefer not to socialise	√					√										
Lacking confidence in school						√										
Expresses feelings about not wanting to live, asking 'why me?', feeling bitter					√											
Night-time fears, night waking, sleeping with parent or nightmares					√							√				√
School refusal (e.g. pretends to be ill to avoid school)															√	
Fussy and restricted about food								√								
Doesn't try at schoolwork								√								

Appendix 4.1 (continued)

Age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Talking about disease or treatment</i>																
<i>'Negative' talk or feelings – (N.B. these wouldn't necessarily be seen as negative in terms of adjustment)</i>																
Blames weight and height problems on steroids				√												
Expresses lack of understanding of reasons for restrictions					√											
Able to express negative feelings to parents about the illness								√								
Describes symptoms or disease sensations to parent							√									
<i>Positive talk or feelings</i>																
Says doesn't mind restrictions, but disappointed about them at times								√								
Doesn't resent taking medication		√														
Doesn't worry about health problems												√				
Sometimes talks about how life would be without asthma/ talks about getting better									√		√					
<i>Being open or private about disease or treatment</i>																
<i>Being open about disease or treatment</i>																
Often deliberately takes medication in front of friends			√													
Doesn't feel he has to hide inhalers									√							
<i>Being private about disease or treatment</i>																
Doesn't like to say he has asthma					√											
Doesn't tell parent when feeling unwell					√											
Avoids taking inhaler with him / her when out with friends									√							
Doesn't express his anxiety to others outside family about health risks								√								

Appendix 4.1 (continued)

Age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Behaviour or emotions during hospitalisation, acute episode or clinic visit</i>																
<i>Hospital admission or acute episode:</i>																
<i>Being accepting, passive or 'brave'</i>																
Mostly accepts treatment without protest	√	√			√			√							√	√
Doesn't say how he feels																√
Accepting and positive									√			√				
Stays calm / doesn't panic during an attack								√				√				
Makes jokes with staff (putting on brave face)																√
Contented to be left by parent															√	
Often felt bored but had 'asthma friends' from regular admissions															√	
Unaware in hospital – too ill to care			√													
<i>Being abnormally withdrawn or regressed</i>																
Reduced / altered talking, playing, eating or toileting in hospital; didn't want parent to leave (not himself)	√						√									√
Clinging											√					
Upset, restless, wakeful							√									
<i>Being overtly anxious / panicky or uncooperative</i>																
Gets very stressed, frightened		√			√		√	√	√		√					
Expresses dislike / upset with needles, likes parent to be present when this is happening		√					√	√	√							
Is uncooperative at times with treatment, panics		√					√				√			√		

Appendix 4.1 (continued)

Age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Transition to recovery phase</i>																
Frustrated at physical restrictions when starting to feel better		✓														
Tries to be normal after hospitalisation												✓				
Just want to go home			✓													
<i>Clinic visits:</i>																
<i>Being angry, upset or uncommunicative</i>																
Anger at doctors – think they are being awkward					✓											
Upset, feeling pressured					✓											
Beginning to object to coming to hospital													✓			
Doesn't like telling doctor he hasn't taken his medicine															✓	
Unable to communicate well in clinic interactions					✓					✓						
<i>Being cooperative, seeing the positive side</i>																
Cooperative, but if parent present													✓			
Likes leaving school early for clinic / enjoys a day out			✓											✓		
Doesn't mind clinic visits, as likes having time alone with parent									✓							
Finds clinic visits reassuring															✓	
Enjoys doing peak flow at clinic											✓					

Appendix 4.1 (continued)

Age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Disease / treatment-related behaviours (not treatment management)</i>																
<i>Minimising focus on disease or treatment (trying to be 'normal'?)</i>																
Tries hard at school / play, despite health problems				√		√										√
Touched horse, claiming didn't know it would be harmful					√											
Objects to being protected (e.g. from cold as a trigger)																√
Started going to rugby training and taken up trumpet (own choice)									√							
Doesn't mind physical restrictions							√									
Doesn't tell parent when feeling unwell					√	√										
<i>Avoiding attacks</i>																
Doesn't want to take some kinds of exercise, as thinks it exacerbates asthma								√						√		
Tells parent when not feeling well		√														
<i>Denying illness</i>																
Doesn't like thinking about responsibilities of illness when older								√								
Relies on friends to recognise when he's becoming ill								√								
<i>Using illness</i>																
Has made asthma worse on purpose, to make parent stay					√											

APPENDIX 4.2: ASTHMA GROUP: Individuality of response: Behaviour or emotion
All children (aged 2 – 16) - Parents' perceptions of child's behaviour or emotion

N.B. (ref x) relates to where (in sequence) the sub-theme was coded in the interview transcript

Respondent number; descriptions of child and own perceptions	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Talking about disease or treatment / being open or private	Behaviour or emotions during hospitalisation, acute episode or clinic visit	Disease/treatment-related behaviours (not management)
A_1 (child – 10 years) Child's behaviour or emotion		A 'home boy' / 'mummy's boy' (ref 4)		Accepted treatment without protest (ref 1) Wouldn't talk or play in hospital first time, didn't want mother to leave) (ref 1) Second hospital visit, mother able to leave, would eat usual food again, would play (ref 2)	
Parent perception of child's behaviour or emotion		Autism and being self-sufficient (ref 4)		Child is being stoic; was so ill, didn't care (ref 1) Not talking or playing was atypical for child (ref 1) Was less withdrawn on 2 nd occasion as he got better more quickly. (ref 2) Mother able to attend to her own needs (shower, etc.) (ref 2)	
A_13 (child – 2 years) Child's behaviour or emotion				Fine, as long as with parent (ref 1) Becoming more anxious, objecting to coming (ref 1)	
Parent perception of child's behaviour or emotion				Child developmentally more aware (last 6 months) (ref 1)	

Respondent number; descriptions of child and own perceptions	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Talking about disease or treatment / being open or private	Behaviour or emotions during hospitalisation, acute episode or clinic visit	Disease/ treatment-related behaviours (not management)
A_3 (Child - 16 years) Child's behaviour or emotion	Being 'stropky', argumentative (ref 3)		Often took medications in front of friends (ref 1, 2)	Likes leaving school early for clinic, happy to come (ref 4) When sick in hospital, 'stoned out' (ref 5)	
Parent perception of child's behaviour or emotion	Being a teenager, fairly normal but sometimes related to approaching attack. (ref 3) Don't take much notice (ref 3)		Liked the effect, i.e. 'Oh, I've got asthma so I take my inhaler'.	Believes child sees clinic as a 'skive off school' (ref 4) In hospital, child was too ill to care, but eager to go home when well (ref 5)	
A_4 (Child – 14 years) Child's behaviour or emotion	Gets cross and frustrated if feels over-protected and unable to do things (ref 3)		Blames weight and height issues on steroids (ref 4)		Tackles all health issues effectively, e.g. tries hard to go to school despite health problems (ref 1)
Parent perception of child's behaviour or emotion	Mother believes she should let her try activities, and she would do it anyway (even if M objected) (ref 3)		Body image issue related to age (ref 4)		'Gutsy child' (ref 1) Likes school (ref 1) Mother impressed with attitude (ref 1)

Respondent number; descriptions of child and own perceptions	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Talking about disease or treatment / being open or private	Behaviour or emotions during hospitalisation, acute episode or clinic visit	Disease/treatment-related behaviours (not management)
A_10 (child – 10 years) Child's behaviour or emotion		Feels 'down' sometimes, leading to him using medication unnecessarily (ref 2)		Stands in corner and grunts in clinic interactions (ref 1)	
Parent perception of child's behaviour or emotion		Need for medication related to depressed emotional state (ref 2)		Related to age, normal. (ref 1)	
A_6 (child – 13 years) Child's behaviour or emotion	Tends to be stubborn and want to do PE etc. even if unwell / denies being unwell (ref 1) Tries to be different / wacky in appearance (ref 3)	Doesn't like going away (ref 4) Lacked confidence e.g. in class at school (ref 5)	Doesn't tell parent if unwell (ref 1)		
Parent perception of child's behaviour or emotion	Child is stubborn and wants to prove something; mother worried she might overdo it (ref 1, 2) Is stubborn as she's had too many years of being told she can't do things (ref 3) Being a teenager makes her want to be different (ref 2, 3), and also wanting to compensate for illness (ref 3)	Child doesn't like unfamiliar situations (ref 4) This is atypical of child, and due to appearance changes (steroids) (ref 5)	Child is stubborn and wants to prove something; mother worried she might overdo it (ref 1, 2) Child is stubborn as she's had too many years of being told she can't do things (ref 3)		

Respondent number; descriptions of child and own perceptions	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Talking about disease or treatment / being open or private	Behaviour or emotions during hospitalisation, acute episode or clinic visit	Disease/ treatment-related behaviours (not management)
A_5 (child – 15 years) Child's behaviour or emotion		Expresses feelings about not wanting to live, asking 'why me?', feeling bitter (ref 1) Expressing fear at night, especially when younger (ref 4)	Doesn't like to say he's got asthma (ref 1) Resented restrictions (ref 3)	Thought doctors being awkward, didn't understand stuff, but getting better (ref 3) Upset at clinic at times, pressured, unable to communicate well (ref 7) When younger, distressed in hospital if mother absent (ref 5, 6) Passive in hospital, accepting (ref 8)	Doesn't tell his mother when he's feeling unwell (ref 2) Doesn't understand how to 'juggle' treatment and lifestyle (ref 2) Made asthma worse on purpose to make parent stay at night (ref 4), or to make them stay in hospital (ref 5) Touched horse, claiming didn't know it would be harmful (ref 9, 10)
Parent perception of child's behaviour or emotion		Parent tries to be encouraging and positive (ref 1) Being a 'sporty' child has made it harder for child (ref 1) Difficult for parent (ref 2) Parent slept with child – due to perception that child was frightened, and very close to mother (ref 4)	Doesn't like to be different (ref 1) Child didn't want to bother parent / parent feels aggrieved because health problem escalates (ref 2) Previously didn't understand reason for restrictions(ref 3)	Poor understanding due to age (ref 3) Mother feels she needs to ask the questions and guide him through clinic experience (ref 7) Young age meant he couldn't cope, but getting better now (ref 5, 6). Lacks energy when ill in hospital, used to treatment (ref 8)	Child doesn't like to think about having asthmatic attack (ref 2) Poor understanding due to age (ref 2, 3) Parent saw bedtime behaviour as manipulative, and felt like 'bad' parent when giving in (ref 4) Felt bad about not having time with other children (ref 5) Lack of understanding or non-compliance? (ref 9, 10)

Respondent number; descriptions of child and own perceptions	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Talking about disease or treatment / being open or private	Behaviour or emotions during hospitalisation, acute episode or clinic visit	Disease/ treatment-related behaviours (not management)
A_16 (child – 4 years) Child's behaviour or emotion		Night waking and sleeping with parent (ref 2, 9)		Upset / restless/ wakeful at hospital (e.g. noise, mask), clinging (ref 6, 7), but cooperative,, doesn't say how he feels (ref 7), doesn't want to eat (ref 8), makes jokes (ref 8)	Dislikes being protected from cold / objects to having scarf over mouth (ref 9) Child likes to play non-stop / be active but avoids attack by not running (ref 4)
Parent perception of child's behaviour or emotion		Uses rewards for sleeping (ref 2); Believes medication, symptoms, hospital visit affected sleep (ref 2, 9)		Child dislikes hospital – gets very stressed (ref 3, 5) Parent feels needs to stay with him, so parent loses sleep (ref 6) He's not himself (ref 8)	Needing to be careful, hard to get him to cooperate (ref 9) Not sure how he would cope with running, so continues to restrict (ref 4)
A_9 (child – 9 years) Child's behaviour or emotion			Sometimes he talks about what his life would be like without asthma (ref) Avoids taking inhaler with him (ref 3, 4)	Doesn't mind going to clinic, and having time with mother there (ref 5) In hospital, accepting, positive (ref 6); disliked blood tests and wanted someone there (ref 6)	Started going to rugby training and taken up trumpet – own choice (ref 2) (both beneficial to improving respiratory function)
Parent perception of child's behaviour or emotion			He'd rather not have it. (ref 1) Doesn't like to admit to self he might get wheezy; it's a reminder he's different (ref 3, 4)	One of 5 children, so time alone with mother is appreciated (ref 5) Child is brave and uncomplaining in hospital (ref 6)	Very pleased started doing this – because friends going to rugby (ref 2) Is a quiet boy (not sporty) but might have been like that without being asthmatic. Doesn't like to admit to self he might become wheezy (ref 3)

Respondent number; descriptions of child and own perceptions	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Talking about disease or treatment / being open or private	Behaviour or emotions during hospitalisation, acute episode or clinic visit	Disease/ treatment-related behaviours (not management)
A_7 (child – 5 years) Child's behaviour or emotion			Describes symptoms to mother e.g. 'Big fat man on my chest' (ref 1)	Goes blue and gets frightened when oxygen levels drop (ref 2) Hates going to hospital, gets scared and uncooperative (ref 4) Distressed with needles (ref 5) Wets bed during coughing fits at night (ref 6)	Doesn't mind physical restrictions (ref 3)
Parent perception of child's behaviour or emotion			Feels sorry for child (ref 1)	Parent feels frightened (ref 2) Needs bribery to make child cooperate (ref 4) Mother thinks she is no help for child if there's needles, as she's scared too (ref 5) Pretty good that doesn't wet bed normally (ref 6)	Knows restrictions are for her own good (ref 3)
A_12 (children – 8 years – another asthmatic 11 years) Child's behaviour or emotion		Has nightmares about severe chest pains before resuscitation (ref 1)	Doesn't worry about health problems (ref 1)	After severe episode, goes back to school and tries to be normal (ref 1) Responds effectively in an attack (e.g. stays calm, initiates controlled breathing) (ref 2)	
Parent perception of child's behaviour or emotion		This is understandable (ref 1)	Calm disposition (ref 1)	Child knows asthma is serious but he tries to be positive (ref 1) Sometimes health care staff don't realise he's as sick as he is (ref 2), his upbringing and personality help him stay calm in emergency (ref 2)	

Respondent number; descriptions of child and own perceptions	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Talking about disease or treatment / being open or private	Behaviour or emotions during hospitalisation, acute episode or clinic visit	Disease/ treatment-related behaviours (not management)
A_15 (child – 13 years) Child's behaviour or emotion		School refusal (i.e. sometimes pretends ill to avoid school) (ref 3)		In hospital when younger for 6 years regularly, often bored but had 'asthma friends', watched videos and happy to be left alone (ref 1, 2) Disliked injections but cooperated (ref 4) Now, finds clinic reassuring although doesn't like telling doctor hasn't taken his medicine (ref 5)	
Parent perception of child's behaviour or emotion		'Trying it on' – gave in (spoiled) but now more firm (ref 3)		Child accepted injections although didn't like them. (ref 4) Child likes clinic because he's had bad experiences elsewhere of misdiagnosis and being ill, but thinks doctors will tell him off if he hasn't been taking his medicine (ref 5)	
A_14 (child – 16 years) Child's behaviour or emotion	Tended to 'play up' other people.			When younger, 'freaked' if needed nebuliser during attack and had to be held down (ref 3), OK now. Tendency to panic during attacks (ref 5)	Doesn't want to take exercise (ref 1)
Parent perception of child's behaviour or emotion	Used to respond to firmness, now doesn't as teenager.			Needed to be firm with child as she 'freaked' / was uncooperative (ref 3) Noise of nebuliser and mask made child panic (ref 5); parent feeling helpless sometimes (ref 5)	Child wanted to keep up with her friends and couldn't, but has now adapted. (ref 1)

Respondent number; descriptions of child and own perceptions	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Talking about disease or treatment / being open or private	Behaviour or emotions during hospitalisation, acute episode or clinic visit	Disease/treatment-related behaviours (not management)
A_2 (child – 4 years) Child's behaviour or emotion	Can 'lash out' and almost be nasty (ref 4, 5)		Doesn't resent pumps (taking medication) (ref 7)	During hospitalisation, panics (ref 1) but majority of time is 'well behaved' with mask etc. (ref 2, 3, 5) Frustrated at not being allowed to run about and not have mask when starting to feel better (ref 3) Can get worked up, upset with needles (ref 4)	Tells parent when not feeling well with his asthma (ref 7)
Parent perception of child's behaviour or emotion	He is frustrated e.g. when can't play (ref 4, 5) Still not feeling well (ref 4) Can't express his feelings due to age (ref 6) Worries he will show aggression towards other children at school, which would be problem as he is large for his age (ref 7)		His age has enabled him to adjust more easily (ref 7)	Child doesn't understand what's happening due to his age (ref 1) Child is well behaved with mask, as he's used to it (ref 2, 5) Parent tries to model appropriate behaviour with needles (ref 4)	
A_11 (child – 7 years) Child's behaviour or emotion			Asks, 'When am I going to get better?' (ref 1)	Child scared and clingy in hospital (ref 2) Child happy about going to clinic, likes doing peak flow – an afternoon out (ref 3)	
Parent perception of child's behaviour or emotion			Might get better, as father did (ref 1).		

Respondent number; descriptions of child and own perceptions	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Talking about disease or treatment / being open or private	Behaviour or emotions during hospitalisation, acute episode or clinic visit	Disease/ treatment-related behaviours (not management)
A_8 (child – 12 years) Child's behaviour or emotion	Eating has been a source of family conflict, but improving (ref 12)	Fussy and restricted about food - doesn't like trying new foods, but getting better (ref 3, 4, 12), took too long over meals (ref 12) Doesn't try hard at schoolwork (ref 11)	Says he doesn't mind restrictions of disease, but shows disappointment sometimes about this (ref 1) Can express negative feelings (ref 1) Doesn't voice his anxiety e.g. about environmental risks to others (ref 5, 6, 7)	Doesn't panic during an attack (ref 8) Doesn't mind skin prick test, but doesn't like injections (ref 13) Will blow in peak flow machine (ref 13) Normally cooperative (ref 13)	Don't like all the responsibilities needed when older, with illness management (ref 2) Doesn't engage in sports / exercise (ref 9) but does cross-country runs (ref 14) Relies on friends to recognise when he's becoming ill (ref 10)
Parent perception of child's behaviour or emotion		Beginning to trust parent (ref 3) as anxious when trying anything new (ref 12) Parent feels satisfaction when child eats (ref 4) Schoolwork is something he can control (ref 11)	Parent believes he does mind restrictions (ref 1) Being naturally cheerful means he doesn't stay negative (ref 1) It is healthy that he expresses negative feelings (ref 1) Child is rather polite (too polite?) (ref 5, 6, 7)	He is articulate (ref 13)	Parent says to child that has to take responsibility if going on own in risky situation (ref 2) Father is not sporty, so maybe he wouldn't be; small so less inclined to sport and/or asthma? (ref 2) Doesn't like to be hurt playing rugby (ref 14). Child is good judge of people, to know who to tell and rely upon (ref 10)

**APPENDIX 4.3: DIABETES GROUP: Individuality of response: Behaviour or emotion
All children (aged 2 – 16)**

(N.B. Behaviour or emotions are either current or experienced in the past)

Age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
Behaviour or emotion component																
<i>Externalising behaviour (non-hospital)</i>																
Being 'stroppy', stubborn or argumentative		√					√			√			√	√		
Shows anger, screaming, crying / sobbing, walks out of situations in anger, swearing, throwing things			√				√				√		√	√	√	
Outburst – 'I hate diabetes'									√				√			
Rebellious							√									
Blaming			√													
Bad moods, irritable				√									√			
Behaves like 'baby' in confrontation with sibling															√	
Conflict with family member (sibling, grandmother)				√										√	√	
Refuses to do PE (appearance-related)								√								
Refuses to get out of bed in AM							√						√			
Rejects offers of help with psychological problems											√					

Appendix 4.3 (continued)

Age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Internalising behaviour (non-hospital)</i>																
Tendency to prefer not to socialise					√								√			
Withdrawn – doesn't communicate as much										√	√					
Expresses feelings of being different, not good enough, lacking confidence															√	
Feels depressed about not being able to lose weight (due to need for diabetes control)			√													
Expresses feelings about not wanting to live, asking 'why me'?, feeling bitter															√	
Night-time fears, night waking, or nightmares						√										
School refusal (e.g. pretends to be ill to avoid school)													√			
Doesn't like having snack at school – gets upset about teasing															√	
*Doesn't feel self-conscious about asking for snack at school						√										
Headaches, tummy aches, leading to time off school (related to stress)												√				
Sometimes in denial about illness, not accepting diabetes								√	√							
Low mood, unhappy, depressed								√			√					
Gets 'fed up' with diabetes sometimes, but doesn't usually complain	√				√	√					√	√				

Contrasting example – not example of internalising behaviour

Appendix 4.3 (continued)

Age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Openness or talking about disease</i>																
Doesn't like telling others or drawing attention to external indicators of diabetes (e.g. giving injection, wearing bracelet, etc.)			√		√		√	√	√	√	√			√	√	
Tends to avoid interaction with other diabetics							√			√			√			
Doesn't mind close friends knowing s/he's diabetic			√						√				√			√
Doesn't mind everyone knowing s/he's diabetic		√				√						√				
Never complains about being diabetic																√
Fed up with feeling different									√							
Frightened of getting complications			√													
Likes showing off bandage after blood test					√											
Sometimes says she wishes she wasn't diabetic						√										
Doesn't like talking about diabetes											√					

Appendix 4.3 (continued)

Age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Behaviour or emotion during hospitalisation, acute episode or clinic visit</i>																
<i>Hospital admission or acute episode:</i>																
Wouldn't eat in hospital															√	
Didn't mind having injections, didn't cry												√				
Worried and frightened when having a hypo, not wanting to be left alone									√							
Uncooperative or difficult behaviour during hypo episodes				√			√									
Disliked being in hospital							√									
Tearful, showing distress about having diabetes			√										√			
Didn't like privacy invasion			√													
Initially thought she would get better													√			
Cried a lot before diagnosis, less after treatment started					√											
Initially frightened, but later able to eat and play					√											

Appendix 4.3 (continued)

Age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Clinic visits:</i>																
Doesn't take on board information								√								
Disliked or was bored with clinic when younger				√	√				√							
Hates talking to people at clinic / often won't talk (or grunts)							√				√					
Objects to going to clinic							√									
Becomes angry and walks out sometimes at clinic							√									
Starting to take an interest in clinic					√											
Nervous or upset about blood tests	√		√		√											
Likes going to clinic, finds it interesting				√												

Appendix 4.3 (continued)

Age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Disease / treatment-related behaviours (not treatment management)</i>																
<i>Using illness</i>																
Pretends to have symptoms to avoid doing something														√		
<i>Minimising focus on disease or treatment (trying to be 'normal'?)</i>																
Incorrectly claims to be unable to manage														√		
Avoids taking snack in bag														√		
May say she's not unwell, when she is, when with strangers		√														
Dislikes reminders about self-care needs							√		√							
<i>Monitoring illness state</i>																
Feels stressed when observing blood sugar readings – worries about hyperglycaemia			√													
Gets excited when finds blood sugar's low													√			
<i>Eating and exercise</i>																
Refuses to eat or hiding food		√		√		√								√	√	
Refuses injections (or in some locations)	√							√							√	
Makes a fuss about not having sweet food sometimes						√									√	
Eats sweets without permission or finds not eating sweets difficult			√												√	
Rebels regarding care (e.g. not doing blood tests)							√									
Doesn't mind food restrictions												√				
Eats an appropriate diet									√							
Became more active after diagnosis									√							
Assertive when adults give wrong advice												√				

Appendix 4.3 (continued)

Age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Eating or exercise</i>																
Races around with others, making herself go hypo		√														
Child behaves responsibly		√			√											
Doesn't take responsibility for illness														√		

APPENDIX 4.4: DIABETES GROUP: Individuality of response: Behaviour or emotion
All children (aged 6 – 16) - Parents’ perceptions of child’s behaviour or emotion

Respondent and perception of parent	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Openness and talking about disease	Behaviour during hospitalisation, acute episode or clinic visit	Disease / treatment-related behaviours
D_14 (child – 13 years) Child’s behaviour or emotion	Stubborn (ref 3, Expressing anger (throws machine at wall, ref 8, screaming fits, rips up flowers, fighting brother, ref 10)		Gets annoyed when others watch her doing her injection (ref 7)		Incorrectly claims unable to manage (ref 2) Pretends to have symptoms to avoid doing something (ref 5, 6) Non-acceptance, e.g. not taking breakfast bar in bag (ref 1, 9) Refuses to eat (ref 3)
Parent perception of child’s behaviour or emotion	Due to ‘just personality’ being teen, also due to ‘hypos’ (ref 4) Accept hurtful things said to them; feeling this is normal; ‘hypo mood’ (ref 10)		Parents encourage her to be assertive and tell them to go away (ref 7)		Attention seeking (ref 2, 5)Child behaves this way to manipulate others (ref 6)Hasn’t accepted illness Parent feels they’re ‘walking on eggshells’, Attributes to manipulation using disease, stubborn personality, not ‘sorting herself out’ (ref 4). Food refusal is frustrating and makes mother feel rejected.
D_8 (child – 13 years) Child’s behaviour or emotion	Refusing PE , complaining about not being able to wear skirts (ref 3)		Hates wearing medical bracelet and finds it annoying (ref 4)	Doesn’t take on board information at clinic (ref 1)	
Parent perception of child’s behaviour or emotion	Embarrassed about bruised legs (ref 3)		Doesn’t like people staring (ref 2) Doesn’t like to wear medical bracelet (ref 4)	Stroppy mood during clinic (ref 1)	

Respondent	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Openness and talking about disease	Behaviour during hospitalisation, acute episode or clinic visit	Disease / treatment-related behaviours
D_10 (child – 16 years) Child's behaviour or emotion	'Stroppy' more often now (ref 1)	Doesn't communicate as much (ref 1)	Tends to avoid interaction with other diabetics (ref 2) Doesn't like to tell others he has diabetes or draw attention to it (ref 3, 4)		
Parent perception of child's behaviour or emotion	'Teenage thing', thinks he's getting on OK / hypo? (ref 1)	'Teenage thing', thinks he's getting on OK / hypo? (ref 1)	Doesn't like to be clumped with diabetics (ref 2) Prefers not to be known as diabetic (ref 3, 4)		
D_16 (child – 15 years) Child's behaviour or emotion			Doesn't mind others (close friends) knowing he's diabetic (ref 1, 3) Never complains about being diabetic / says 'it could be worse' (ref 2)		
Parent perception of child's behaviour or emotion			He has become more comfortable with it (ref 1, 3) Parent feels child is mature and she is the one who finds it distressing instead (ref 2),		

Respondent	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Openness and talking about disease	Behaviour during hospitalisation, acute episode or clinic visit	Disease / treatment-related behaviours
D_15 (child – 8 years) Child's behaviour or emotion	Expresses anger, tantrums, sobbing (ref 1, 2,3,9,10,11) Behaves like 'baby' when confrontation with sister (ref 2)	Expresses feelings of being different, not good enough, feeling different, incapable, lacking confidence, wishing he was dead, asking 'why me?' (ref 1, 5) Doesn't like having snack at school, as gets upset by teasing about this (ref 5)	Doesn't like injecting in front of others (ref 13) Likes mother not coming to school to inject him (ref 6)	Wouldn't eat in hospital (ref 4)	Food refusal or hiding food (ref 1, 9, 10, 12) Making a fuss sometimes when told can't have something (e.g. ice cream) (ref 7) Eats sweets at school without waiting (ref 8) Doesn't take responsibility / mother has to 'push' (ref 9) Sometimes refused different location of injection, showing anger & distress (ref 13, 14)
Parent perception of child's behaviour or emotion	Due to diabetes (ref 2, 10) Feelings coming out in the 'wrong way' (ref 1), child can't take criticism (ref 11) Parent tries to take no notice of behaviour and be hard (ref 2, 12), and praises him for good behaviour, but this makes little difference (ref 3). Feeling others not recognising parents' needs (ref 1) Parent finding it difficult to deal with (ref 1)	Parent doesn't know how to respond to this, seeking help; heartbreaking to hear child express wish to be dead (ref 1) Feeling others not recognising parents' needs (ref 1) Parent finding it difficult to deal with (ref 1)	Doesn't like to be different – other kids cruel; Doesn't like child being treated differently (ref 5) He wants to be normal (ref 6)	Fussy eater (ref 4)	Parent sees child in role of 'baby' in illness, stuck between growing up and not (ref 1) Food refusal form of effort to take control (ref 12) Mother 'tearing hair out' (ref 12) Not so important he eats sweets because he is an active boy, but a worry when 'running high' (ref 8) Child has emotional 'struggles' (ref 9) Mother tries to insist on different locations of injection, without effect (ref 14) Tried to get him to take control, using injecting pens (ref 13) Doesn't like change (ref 14)

Respondent	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Openness and talking about disease	Behaviour during hospitalisation, acute episode or clinic visit	Disease / treatment-related behaviours
D_12 (child – 10 years) Child's behaviour or emotion		Headaches, tummy aches, leading to time off school (related to worry / stress?) (ref 7)	Only once showed serious upset about the diagnosis (ref 2); otherwise, has a few 'I hate diabetes' days (ref 2) Fairly open about doing injections / doesn't mind others watching, she'll think it's good for others to see (ref 6) Happy that everyone at school knows (ref 7)	Didn't mind having injections and didn't cry (ref 1)	Assertive when adults give incorrect advice about treatment (ref 4) Never fussed about restrictions of sweets or food issues (ref 5)
Parent perception of child's behaviour or emotion		Difficulties with inconsistency of teachers at school made her stressed, leading to internalising symptoms (ref 7)	Came to terms with diagnosis very quickly and accepted it, perhaps because of being so young (ref 2) Feels sorry for child (ref 3) Copes well because 'lovely kid, friends, active, bouncy, outgoing' (ref 3) More mature than other friends (ref 4) We don't make her cover up (ref 6) Even though known as diabetic, continues to be popular girl (ref 7, 8) and has supportive peer group (ref 8)	She's a 'tough cookie', not a cry baby (ref 1) Parent felt clear explanation of rationale needed (ref 1)	Outgoing, mature (ref 4) She is treated more like an adult in the family (ref 4) Characteristics of child (ref 5)

Respondent	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Openness and talking about disease	Behaviour during hospitalisation, acute episode or clinic visit	Disease / treatment-related behaviours
D_9 (child – 16 years) Child's behaviour or emotion		Sometimes in denial about illness / 'I hate diabetes/ fed up' etc. (ref 3, 7)	Child doesn't like a fuss if 'low', or to show others her snack box (ref 1) 'Fed up' with feeling different (ref 2) Didn't go on sleepovers as didn't want people to know she had diabetes (ref 3)	Worried and frightened when had hypo, didn't want to be left or go to school afterwards (ref 6) Still wants mother when not feeling 100% (ref 6) Used to not like going to clinic but now OK (ref 11)	Eating appropriate diet not a problem (ref 2) and became more active after diagnosis (ref 2) Dislikes mother advising her about self-care (e.g. not drinking excess alcohol, eating food, testing urine) (ref 4, 5, 8) Tends to do her tests etc (ref 11)
Parent perception of child's behaviour or emotion		Acknowledges child's feelings, also thinks feelings related to being teenager (ref 3)	Good that teacher supported this (ref 1) Parent feels upset that child is upset about being different (ref 2, 3, 9) Doesn't mind close people knowing, but not everyone, partly because of common misunderstandings (ref 9)	At younger age, felt was being 'told off' at clinic (ref 11)	Likes vegetables (ref 2) Recognises child doesn't like being advised about self-care (ref 4, 8) Feels need for child to do self-care for her peace of mind (ref 5, 8)

Respondent	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Openness and talking about disease	Behaviour during hospitalisation, acute episode or clinic visit	Disease / treatment-related behaviours
D_7 (child – 15 years) Child's behaviour or emotion	Although will have long period when 'OK', typically angry, rebelling, stubborn (ref 1, 2, 9, 14) Throws tantrums at school or walks out (ref 4, 11)	Never wanted to accept diabetes (ref 1) Low mood (ref 9)	Refuses to go on diabetes trips (ref 5) Until recently, refused to go out where he might have to inject in front of others (ref 6, 7)	Hates talking to people at clinic – walks out sometimes. Won't talk usually (ref 4) Objects to going to clinic (ref 12, 13) During hypo episode, uncooperative (ref 8) Didn't like being in hospital (ref 14)	Rebels regarding care (ref 2) Doesn't like being reminded about blood tests (ref 3)
Parent perception of child's behaviour or emotion	Related to his father dying prior to his own diagnosis couldn't accept another thing to deal with. (ref 1) Has had anger management support to help him but didn't help much (ref 4) When things go badly at school, anger etc. gets worse at home and vice versa (ref 9) Feels like that anger is always there (ref 9) Some behaviour problems due to low blood sugar (ref 10, 11) Hasn't accepted diagnosis (ref 14)	Related to his father dying prior to his own diagnosis, couldn't accept another thing to deal with. (ref 1)	Lacks confidence in going on diabetes trips. (ref 5) Starting to be willing to inject when out because older (ref 6, 7)	Relates to his feeling angry (ref 4) Doesn't like having blood and urine tests at clinic, the bus trip or time involved (ref 12) The hypo affects his behaviour control (ref 8)	Feels need to 'keep on top' as can't rely on child to do care. (ref 2) Child wishes mother would 'keep quiet' (ref 3)

Respondent	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Openness and talking about disease	Behaviour during hospitalisation, acute episode or clinic visit	Disease / treatment-related behaviours
D_3 (child – 13 years) Child's behaviour or emotion	Earlier, was very very angry, hysterical, swearing and blaming (ref 5)	Gets bitterly upset, heartbroken, beside herself sometimes (ref 1) Depressed at not being able to lose weight (ref 4)*	Open about illness (ref 1) Feels scared sometimes when reading about complications, as BG often is high (ref 3) Says doesn't like to be different (ref 3)	Very tearful, saying hated diabetes and didn't like privacy invasion (ref 2)	Feels stressed when observing blood test readings – worried it will be high (ref 3) Found it difficult not to have sweets (ref 3) Has trouble with hypos, so eats too many sweets and can't lose weight (ref 4)*
Parent perception of child's behaviour or emotion	Writing letter to community nurse helped (ref 5)	Being quite independent makes it harder for her (ref 1), but generally strong Wants to be like other teen friends, and thinner (ref 4) Diabetes is cause of weight problem (ref 4)	Strong person (ref 1) and mature, forward thinking (ref 6) Diabetes has made her grow up earlier than she would have done (ref 6)	Harder being a teenager (ref 2)	Friends supported her (ref 3)

Respondent	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Openness and talking about disease	Behaviour during hospitalisation, acute episode or clinic visit	Disease / treatment-related behaviours
D_13 (child – 12 years) Child's behaviour or emotion	'stropy' / irritable in the mornings, refuses to get up (ref 1) 'Lots of tears' / outbursts / I hate diabetes (ref 3, 7)	Has become more cautious, more of a 'home girl', won't stray far (ref 2) School problems – wanting to come home, saying ill (ref 4)	Refuses to go to Diabetes UK holidays (ref 5) Doesn't mind doing blood tests in front of friends, but says they don't understand (ref 6)	Initially unrealistic about outcome near diagnosis time (will get better shortly) (ref 3) Distressed about diagnosis when in hospital (ref 3)	Gets excited when blood sugar is low (ref 7) 'In a dream world' sometimes and doesn't take medication in AM (ref 7)
Parent perception of child's behaviour or emotion	'teenage thing'? (ref 1) Concerned that she will rebel eventually in illness management (ref 7) Don't shout back when having 'outburst'	Think she's scared to go far in case she has a hypo or forgets anything (ref 2) Too overprotective? (ref 2) Feel sad that childhood has been lost, and had to grow up quickly (ref 2) Anxiety as new school + diabetes (ref 4)	Parent feels child being forced to take responsibility early has made her become more mature, but she's been mature for her age anyway (ref 2) Too anxious to go on Diabetes UK holidays (ref 5)	Lack of understanding – dreadful to have to tell child that won't get better (ref 3) She was starting to realise the implications (ref 3)	Feels it is a real achievement when her blood sugar is low (ref 7) Need to nag to get her to take medicine (ref 7)

Respondent	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Openness and talking about disease	Behaviour during hospitalisation, acute episode or clinic visit	Disease / treatment-related behaviours
D_5 (child – 10 years) Child's behaviour or emotion		A 'loner', doesn't like to mix (ref 1)	Says he wishes he didn't have diabetes so he could eat (ref 4) Liked to show his bandage (following blood test) at school (ref 5) Doesn't like to do his injection in front of others (ref 5)	Cried a lot prior to diagnosis, whingey (ref 2) Gets bored at clinic , but starting to show an interest (ref 5) Nervous about blood test, proud when it was finished (ref 5) Frightened during hospital admission but OK afterwards, able to eat and play (ref 5)	Responsible (ref 3)
Parent perception of child's behaviour or emotion		Asberger's	Doesn't like doing injection because has to pull down trousers (ref 5)	Diabetes (ref 2) Getting older helps him be more interested (ref 5)	
D_6 (child – 8 years) Child's behaviour or emotion		Screaming, nightmares (ref 4, 5) Gets 'fed up' at times (ref 6)	Doesn't mind others watching her do injections (ref 2) Doesn't feel self-conscious about asking for snack at school. (ref 7) Doesn't get upset because of having diabetes, except if hypo (ref 8) Occasionally says, 'I wish I wasn't diabetic' (ref 8)		Can be difficult about not wanting to eat or eat the wrong things (ref 1, 3) Occasionally upset at having injections (ref 8)
Parent perception of child's behaviour or emotion		Due to hypos? (ref 4, 5) Horrible, but in one way, think it's funny (ref 4). Being fed up is like any child who can't have own way (ref 6)	Child regards injections as normal, as she was diagnosed age 2 (ref 2)		Mother tells her she has to take responsibility, it's her own fault if she goes low (ref 1, 3) Will tell others when she's unwell (ref 7)

Respondent	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Openness and talking about disease	Behaviour during hospitalisation, acute episode or clinic visit	Disease / treatment-related behaviours
D_2 (child – 8 years) Child’s behaviour or emotion	‘Stroppy’ (ref 1)				Sometimes won’t eat, including at night when wakened (ref 1, 3, 4) or would only eat pita and chocolate spread (ref 5) Races around when with others, which makes her go hypo (ref 4) Usually takes responsibility (ref 4, 6) but may say not unwell when she is, when with strangers (ref 4) Never lies with parent about diabetes (ref 6)
Parent perception of child’s behaviour or emotion	Strong minded individual, ‘up and down’ temperament, also moved house and lots of changes and felt ill (ref 1, 2)				Refused because wanted to play (ref 1) or sleep (ref 3). Parent felt scared (ref 3) Excitable child, highly strung (ref 4)
D_1 (child – 9 years) Child’s behaviour or emotion			Tells others he has diabetes – likes to see their reaction. (ref 3) Accepts limitations of diabetes (ref 4)	At clinic, shows upset due to fear of needles, ‘freaks’ / struggles (but getting better) – (ref 1, 2)	Tends to get upset with injections (see other ref?)
Parent perception of child’s behaviour or emotion				Parent upset they can’t show they’re upset (ref (1, 2) Perceives play nurse helps him cope (ref 2)	

Respondent	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Openness and talking about disease	Behaviour during hospitalisation, acute episode or clinic visit	Disease / treatment-related behaviours
<p>D_11 (child – 15 years) Child’s behaviour or emotion</p>	<p>Angry (ref 2)</p>	<p>Very unhappy / miserable for 2 years – depressed? (ref 2)</p> <p>Rejects psychological help; doesn’t think he needs it (ref 2)</p>	<p>Finds it difficult to talk about diabetes, resents being diabetic, wants to be like others. (ref 1)</p> <p>Being small makes him feel more different (ref 4)</p> <p>Resented brother going to sleepover when he couldn’t (ref 3)</p>	<p>At clinic, tends to grunt in response but getting (ref 4)</p>	
<p>Parent perception of child’s behaviour or emotion</p>		<p>Parent worries child may have depression (ref 2)</p> <p>Is this due to diabetes or not? May feel under pressure (ref 1) and teenager (ref 2)</p> <p>Father’s poor mental health may contribute (ref 1)</p> <p>Difficult for a parent to watch child struggling with sadness (ref 2)</p>	<p>He feels the diabetes makes him stand out as different (ref 1)</p> <p>Doesn’t understand why can’t go on sleepovers, which is because it is too scary for the other parents (ref 2)</p>	<p>Behaviour due to being teenager (ref 4). Getting better because feeling better about himself, as he’s growing (ref 4).</p>	

Respondent	Externalising behaviour (non-hospital)	Internalising behaviour (non-hospital)	Openness and talking about disease	Behaviour during hospitalisation, acute episode or clinic visit	Disease / treatment-related behaviours
<p>D_4 (child – 6 years) Child’s behaviour or emotion</p>	<p>Bad moods (ref 3) ‘Affected psychologically’ (ref 3) ‘At loggerheads / not nice with grandmother’ (ref 4)</p>			<p>In acute episode, behaviour is difficult (ref 1) He later becomes his ‘sweet lovely self’ (ref 1) Likes going to clinic and finds it interesting, chance to play (although at 2, made a fuss about height measurement) (ref 5)</p>	<p>Sometimes won’t eat (ref 2)</p>
<p>Parent perception of child’s behaviour or emotion</p>	<p>Too high or too low blood sugar (ref 3) Doctors don’t tell you because they don’t want to scare you (ref 3) Grandmother has unrealistic expectations of child (ref 4)</p>			<p>Parent sees it as good that child is interested in own health (ref 5)</p>	<p>Father thinks child should eat what he’s given; mother thinks she should keep offering different foods until he eats – leads to conflict.</p>

APPENDIX 4.5: ASTHMA GROUP: Effects on child's social life: All ages (2-16 years)

Age (years)	2	4	4	5	7	8	10	10	11	12	13	13	14	15	16	16
Participant number	A_13	A_2	A_16	A_7	A_11	A_12	A_1	A_9	A_10	A_8	A_6	A_15	A_4	A_5	A_3	A_14
PE / sports																
Participates less in sports than other children; child minds		√	√											√		
Participates less in sports than other children; child has adapted to this								√								√
Occasionally misses PE due to symptoms; PE teacher is intolerant												√				
Participates in sports the same as other children, but may find it hard to keep up or have to stop to take medication											√		√			
Participates in sports the same as other children and has no problem now (although did previously)									√							
Activities with friends / outings involving exposure to allergens, cold or excessive exercise																
Unable to go horse-riding			√													
Has gone on farm trip after discussing management of attack with teacher								√								
Can't usually go to friends houses who have pets; they come to child's house instead; child accepts this											√					
Can't usually go to friends houses who have pets; child finds this upsetting										√						
May be unable to play outside with friends (or has to play close by) / go on trips outside due to the cold, allergens or physical demands			√	√	√						√			√		√
Could go on residential trips if accompanied by parent														√		

Appendix 4.5 (continued)

Age (years)	2	4	4	5	7	8	10	10	11	12	13	13	14	15	16	16
Participant number	A_13	A_2	A_16	A_7	A_11	A_12	A_1	A_9	A_10	A_8	A_6	A_15	A_4	A_5	A_3	A_14
Visiting friends / staying overnight with friends																
Can stay at close friends' houses overnight as other parents can cope											√					
Can go away with friends overnight as independent with giving own medication												√			√	
Visits friends' houses in daytime and others come to his			√				√					√				
Doesn't stay at friends' houses overnight							√							√		
Parties																
Can't always go to parties because of asthmatic symptoms or allergies										√						
Goes to birthday parties but parents need to know how to manage medication and avoid inducing symptoms					√											
When younger, attended parties; teased due to nebuliser												√				
School trips																
Child is able to go on school day trip without parent						√	√									√
Child is unable to go on school day trips without parent				√												
Hasn't been on one or more residential school trips, as parent worries (e.g. allergy risks) or school won't take responsibility for medication					√	√				√						
Has been on one or more residential school trips without parent							√									

Appendix 4.5 (continued)

Age (years)	2	4	4	5	7	8	10	10	11	12	13	13	14	15	16	16
Participant number	A_13	A_2	A_16	A_7	A_11	A_12	A_1	A_9	A_10	A_8	A_6	A_15	A_4	A_5	A_3	A_14
Other social activities																
Doesn't go to sweet shop with friends due to allergy risk										✓						
Very careful about eating in restaurants due to allergy risk							✓			✓						
Misses favourite games sometimes due to clinic appointments										✓						
Doesn't or rarely visits relatives (although siblings do) – due to medications or relative's pets					✓		✓							✓		
Visits relatives with pets, but stays away from the pets								✓								
Does babysitting; worries about needing to cancel due to illness													✓			
Is in school play; worries about needing to cancel due to illness													✓			
Difficulties singing in choir due to coughing, but overcame the problem													✓			
Walks / drives to school with parent rather than friends when slightly unwell				✓										✓		
Former impact on social activities																
Previously couldn't go on picnics due to absence of electrical plug (needing to plug in the nebuliser)												✓				
Previously, couldn't do things other kids did, or not as easily								✓								
Previously minded not being able to do sport with friends																✓

Appendix 4.5 (continued)

Age (years)	2	4	4	5	7	8	10	10	11	12	13	13	14	15	16	16
Participant number	A_13	A_2	A_16	A_7	A_11	A_12	A_1	A_9	A_10	A_8	A_6	A_15	A_4	A_5	A_3	A_14
School progress																
Missed a lot of school due to asthma-related illness		√		√				√			√	√		√		
Doesn't miss school due to illness									√							
<i>N.B. This probably will come under category: child's relationships with friends and at school (merge codes?)</i>																
School relationships																
Friend is diabetic – they both feel different, so support each other											√					
Get teased because of appearance on steroids											√					
Get teased when unable to play (breathless)														√		

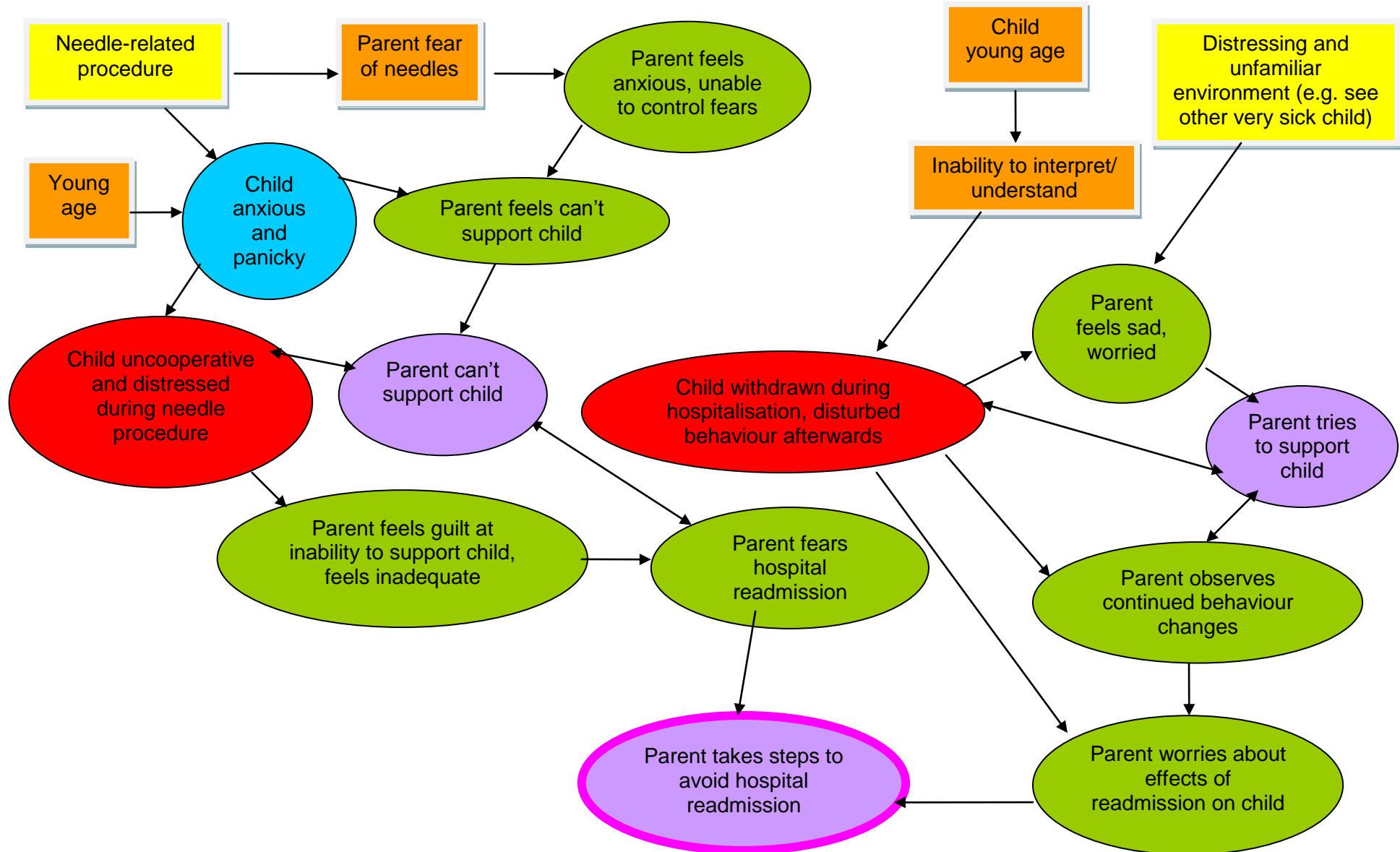
APPENDIX 4.6: DIABETES GROUP: Effects on child's social life: All ages (6-16 years)

Age (years)	6	8	8	8	9	10	10	12	13	13	13	15	15	16	16	16
Participant number	D_4	D_2	D_6	D_15	D_1	D_5	D_12	D_13	D_3	D_8	D_14	D_7	D_11	D_9	D_10	D_16
PE / sports																
Fully engages in various sports					√				√						√	√
Sometimes won't go to a 'away' match if he has to give an injection whilst away from home												√				
Plays football, but it is less spontaneous - has to think more in advance					√											
Activities with friends / outings																
Rarely goes out to restaurants with friends															√	
Socialises in group activities (cubs, football)				√												
Visiting friends / staying overnight with friends																
Once or rarely spends the night with one family / individual		√					√			√						
Stays overnight at friends' house								√				√				
Never stays overnight at friends' house						√					√		√			
Can play at only a few friends' houses and for a short time (other parents worried)					√											
Parties																
Can go to parties, but parent has to find out what is being eaten, and check host parent can cope with a hypo		√														
Can go to parties – parents tell hosts he can eat what he wants, and they'll sort the effects out later						√										
Child hasn't been invited to parties (or invitation withdrawn) when other parent discovers he has diabetes					√											

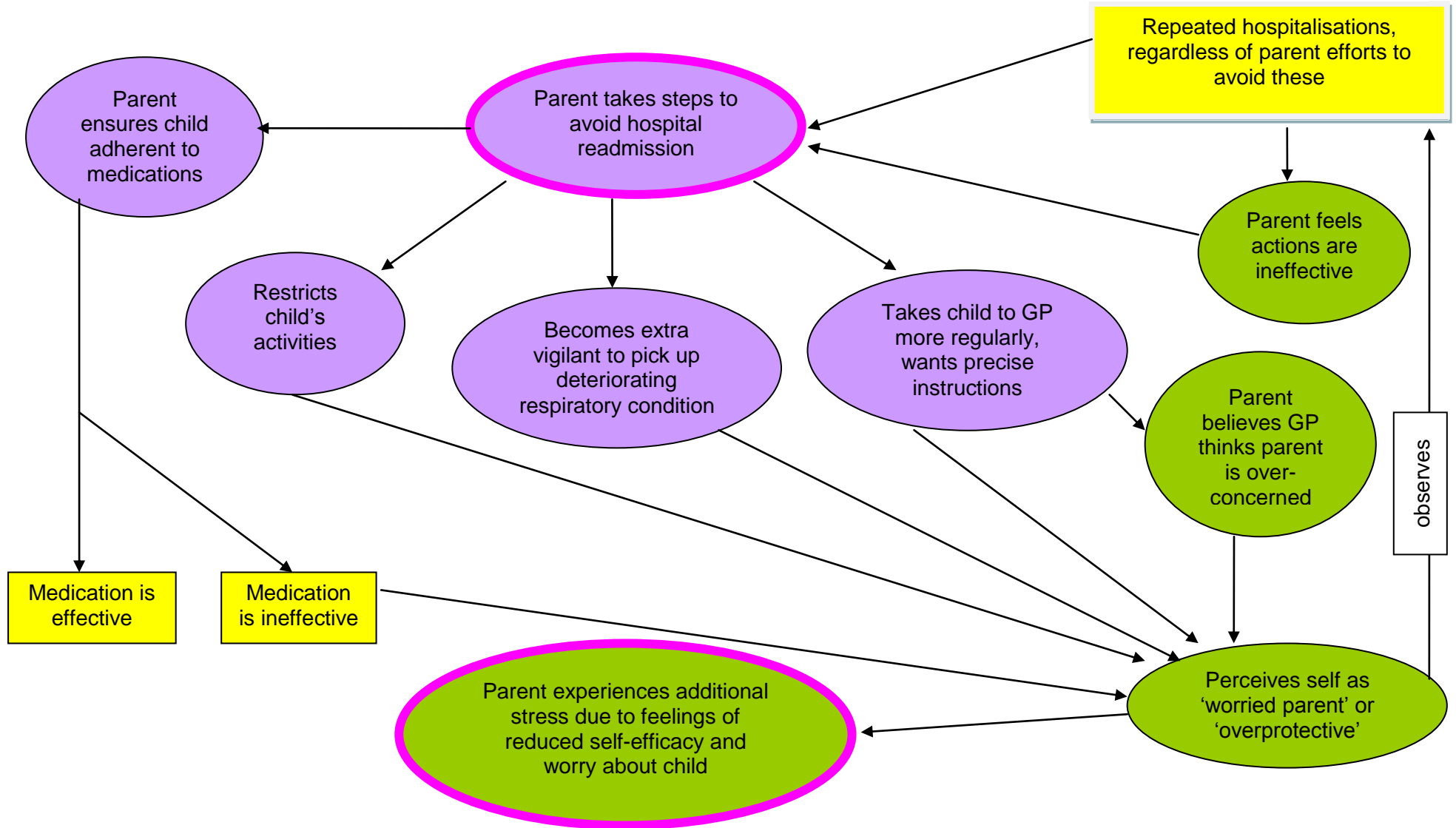
Appendix 4.6 (continued)

Age (years)	6	8	8	8	9	10	10	12	13	13	13	15	15	16	16	16
Participant number	D_4	D_2	D_6	D_15	D_1	D_5	D_12	D_13	D_3	D_8	D_14	D_7	D_11	D_9	D_10	D_16
School trips																
Has been on residential trip, with parent accompanying because school wouldn't take responsibility							√									
Has been on residential trip without parent								√					√	√	√	
Hasn't been on residential trips at all (because child can't give own injections)				√	√											
Has some day trips/ swimming where parent has to accompany			√		√		√									
Has some day trips without parent			√													
Other social activities																
Never left alone at high risk times										√			√			
Generally socialises less because of diabetes										√						
Doesn't really affect social life at all, except having to remember medication etc.														√		√
Doesn't stay at relatives overnight (whilst sibling does)						√										
Former impact on social activities																
Formerly couldn't go on school trips without parent													√			
Formerly wasn't invited to parties because other parent couldn't cope													√			
School progress																
Missed a lot of school due to diabetes					√								√			
Doesn't miss school due to illness																

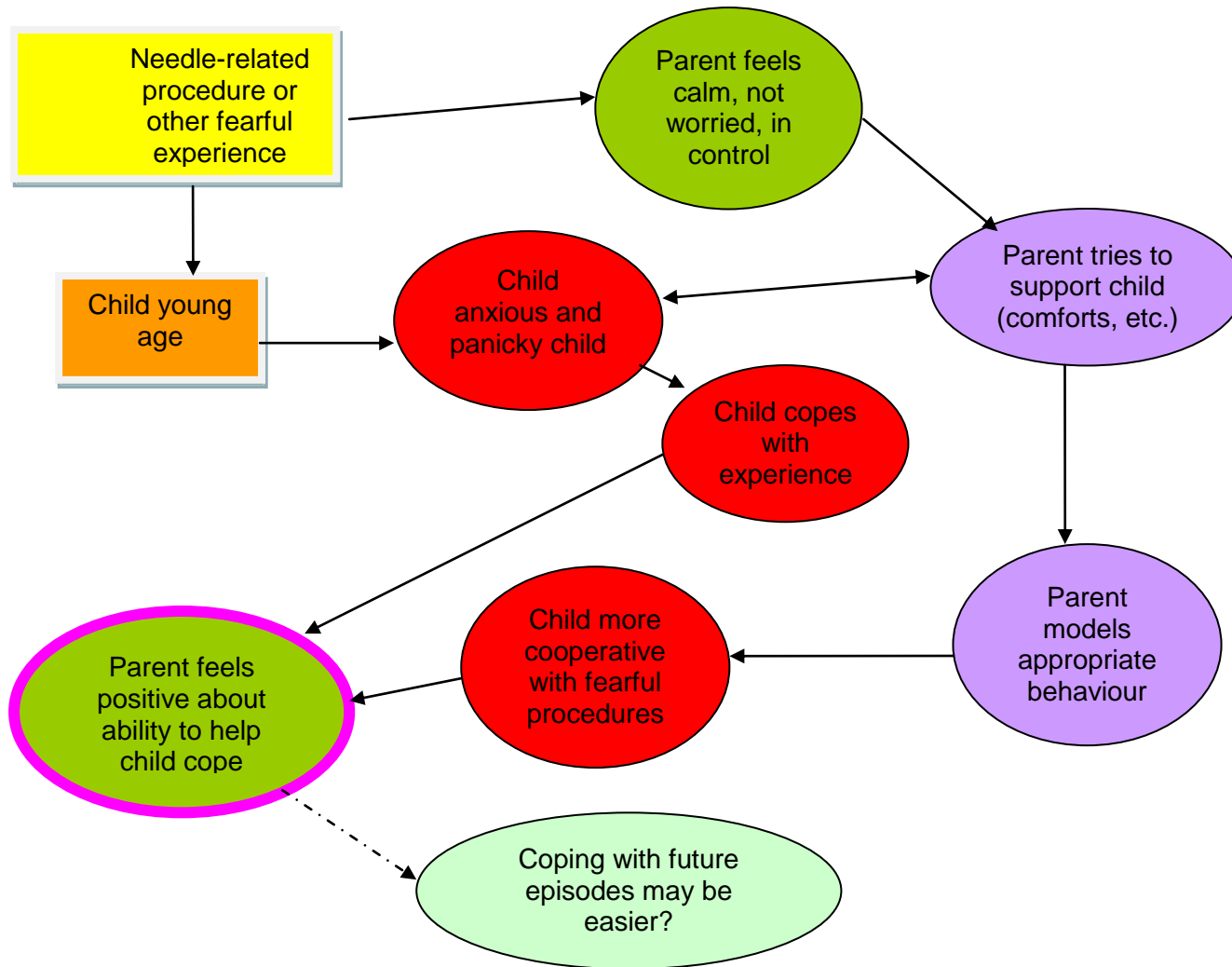
Appendix 4.7: Schematic Diagram 1a: Behaviour and Emotions during Acute Episode or Hospitalisation ('negative') – Asthma Group



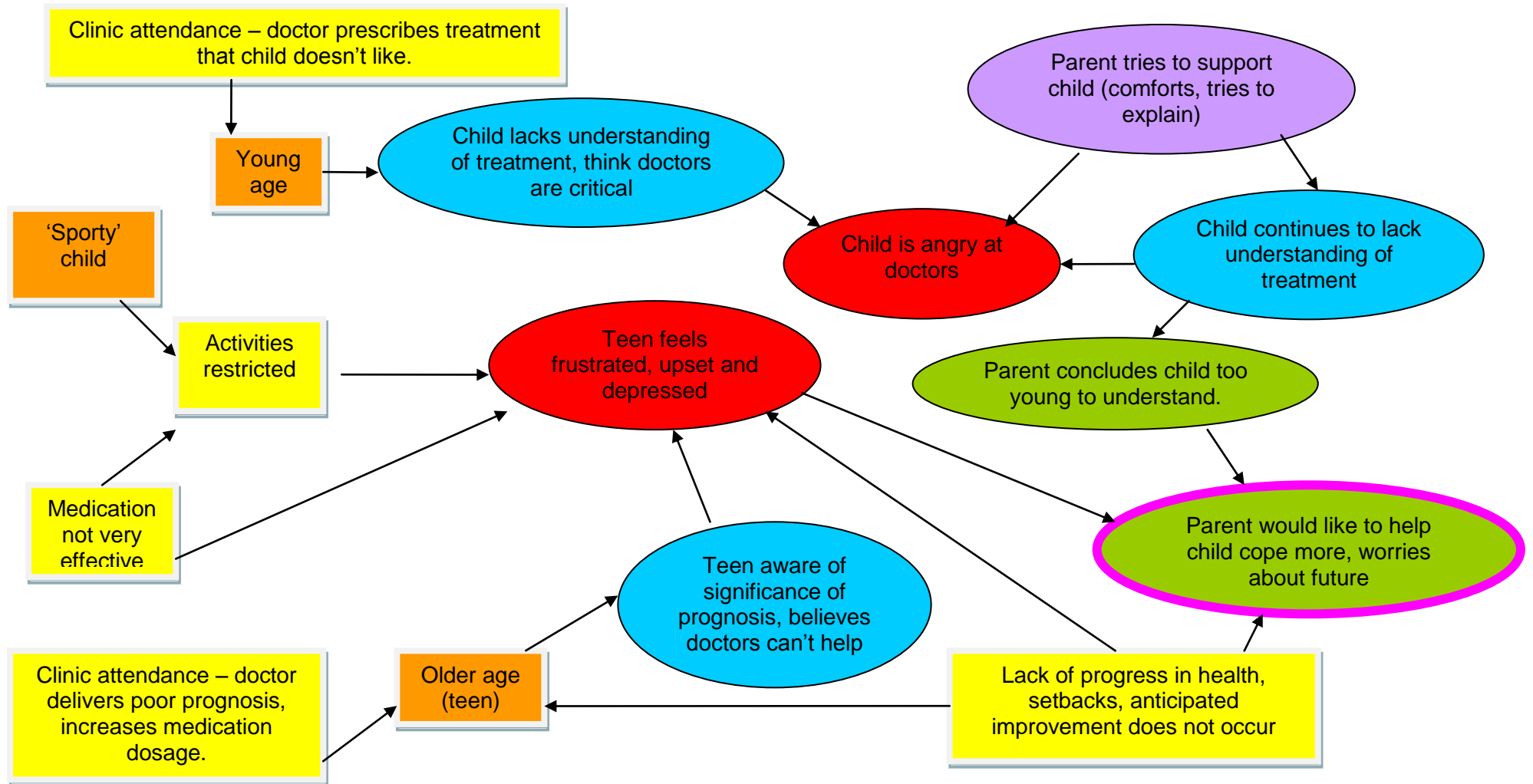
Appendix 4.7: Schematic Diagram 1b: Behaviour and Emotions during Acute Episode or Hospitalisation ('negative') – Asthma Group



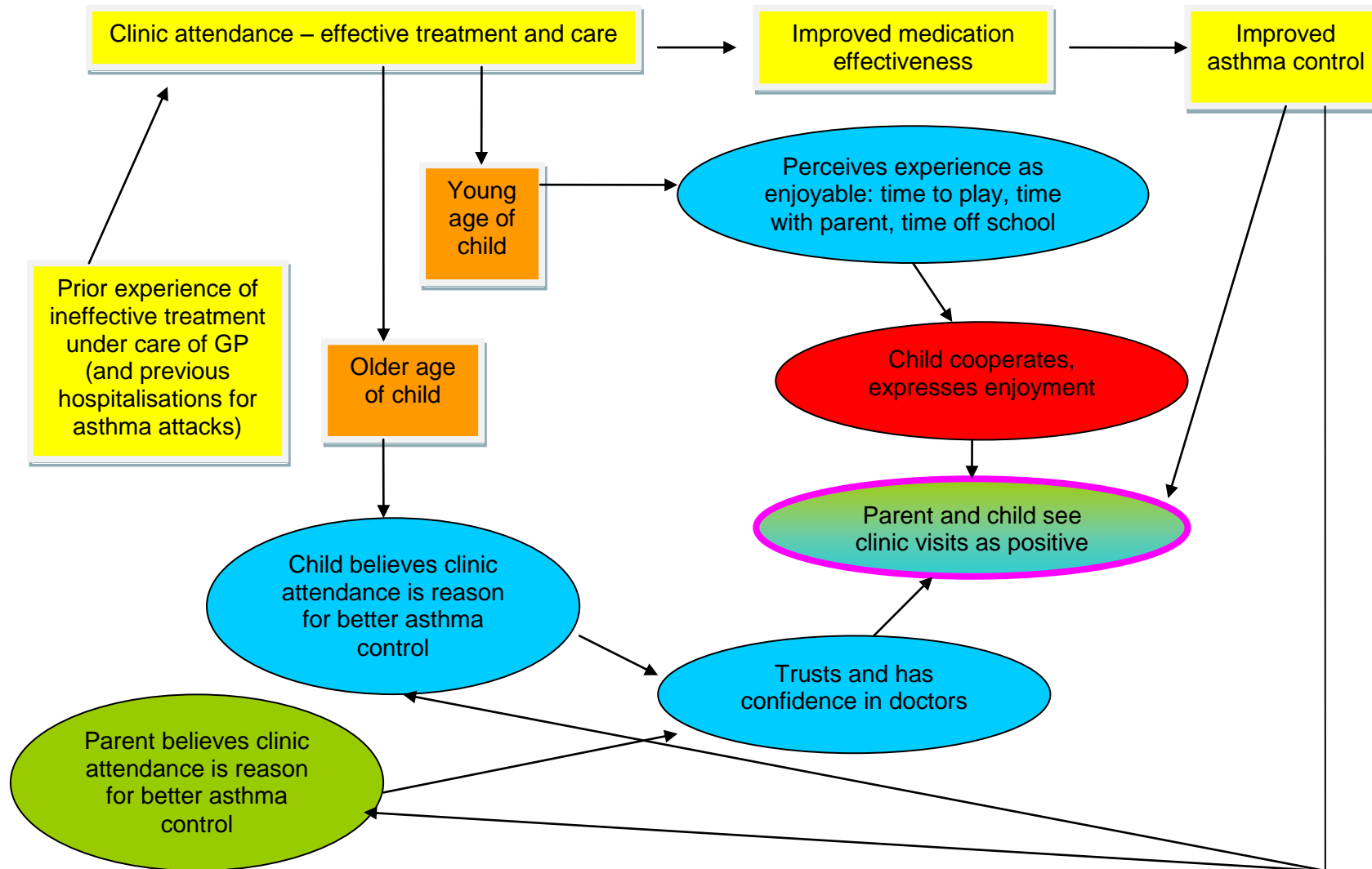
Appendix 4.8: Schematic Diagram 2: Behaviour and Emotions during Acute Episode or Hospitalisation ('positive') – Asthma Group



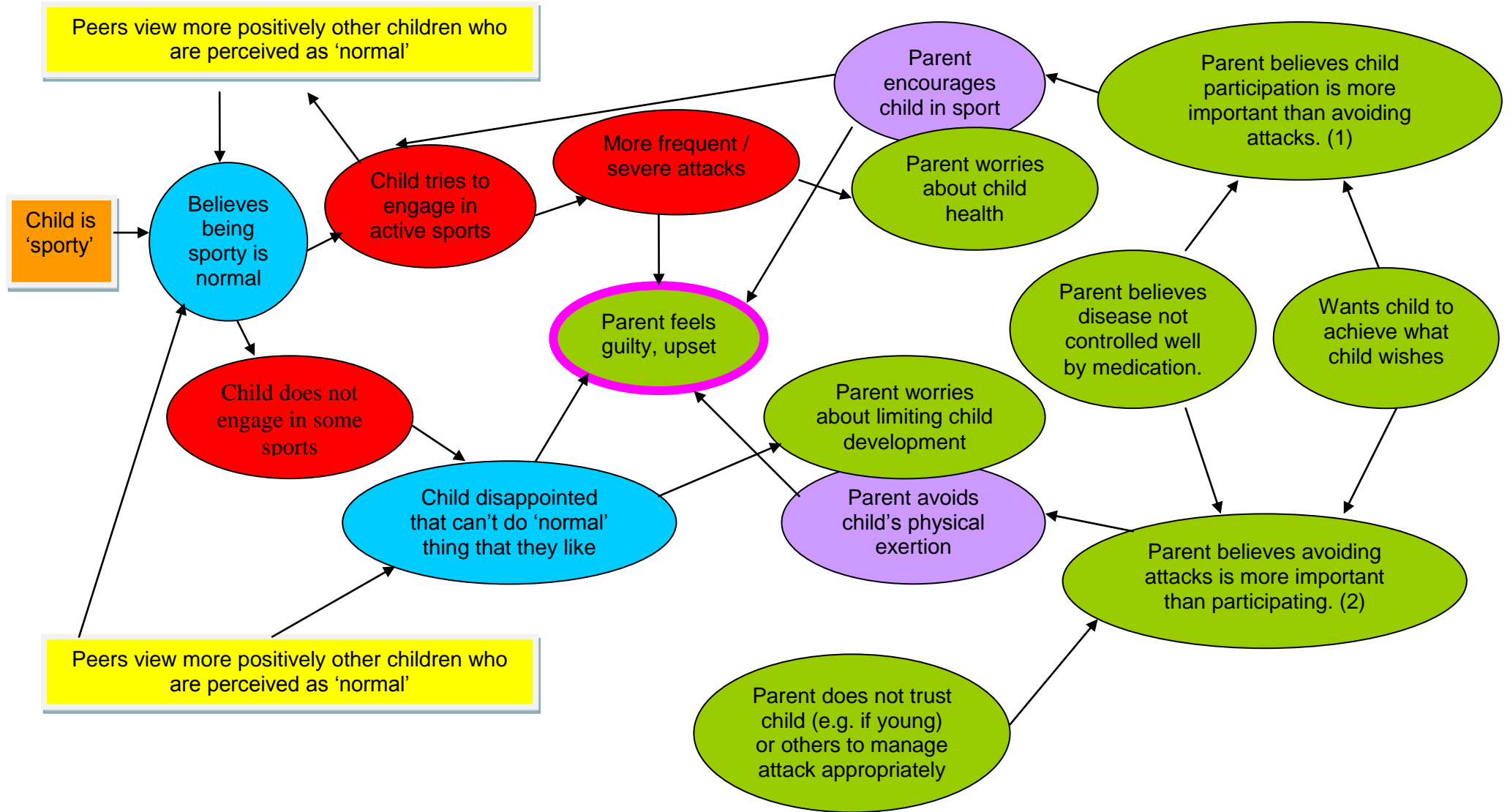
Appendix 4.9: Schematic Diagram 3: Behaviour and Emotions during Clinic ('negative') – Asthma Group



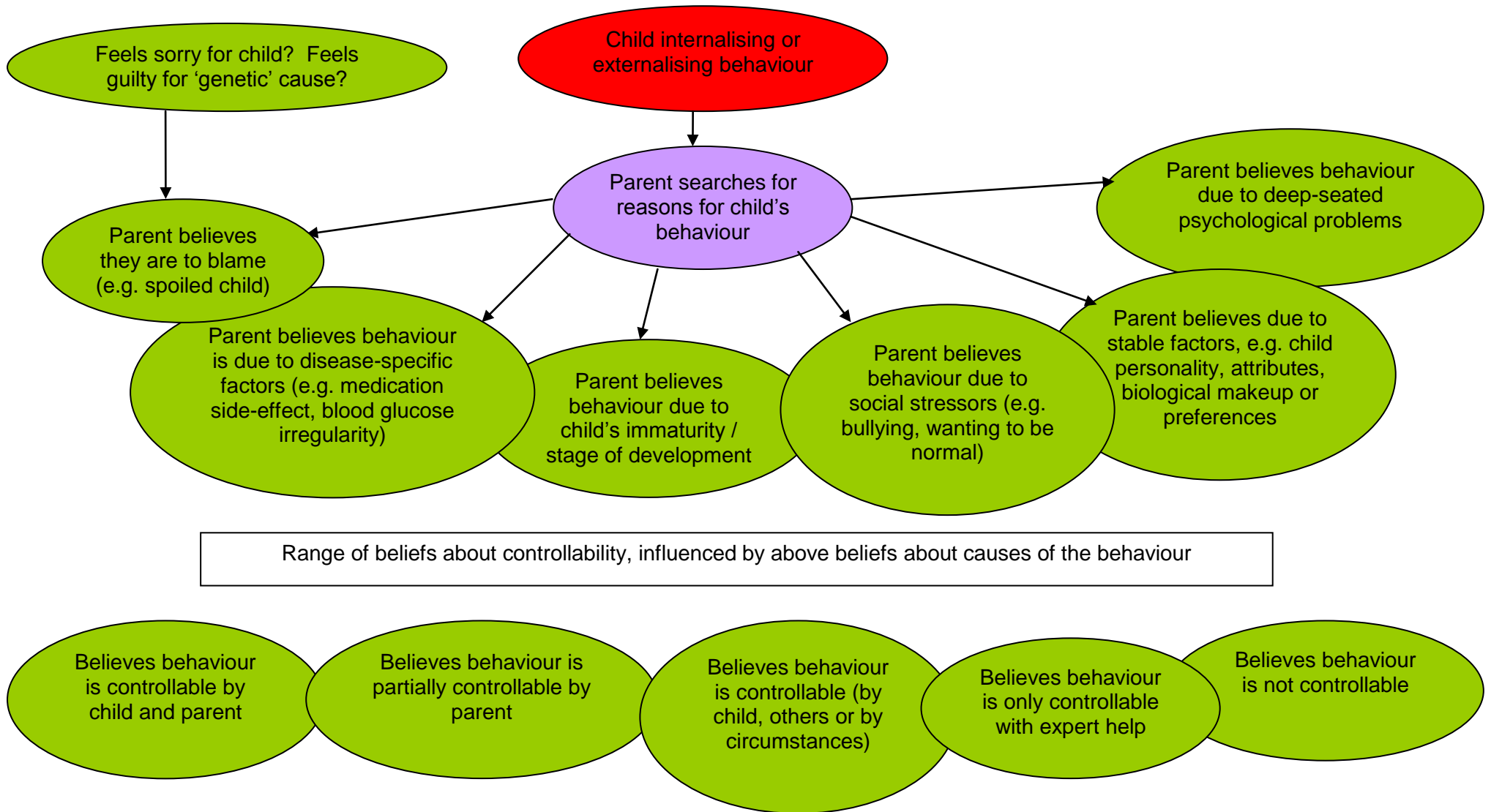
Appendix 4.10: Schematic Diagram 4: Behaviour and Emotions during Clinic ('positive') – Asthma Group



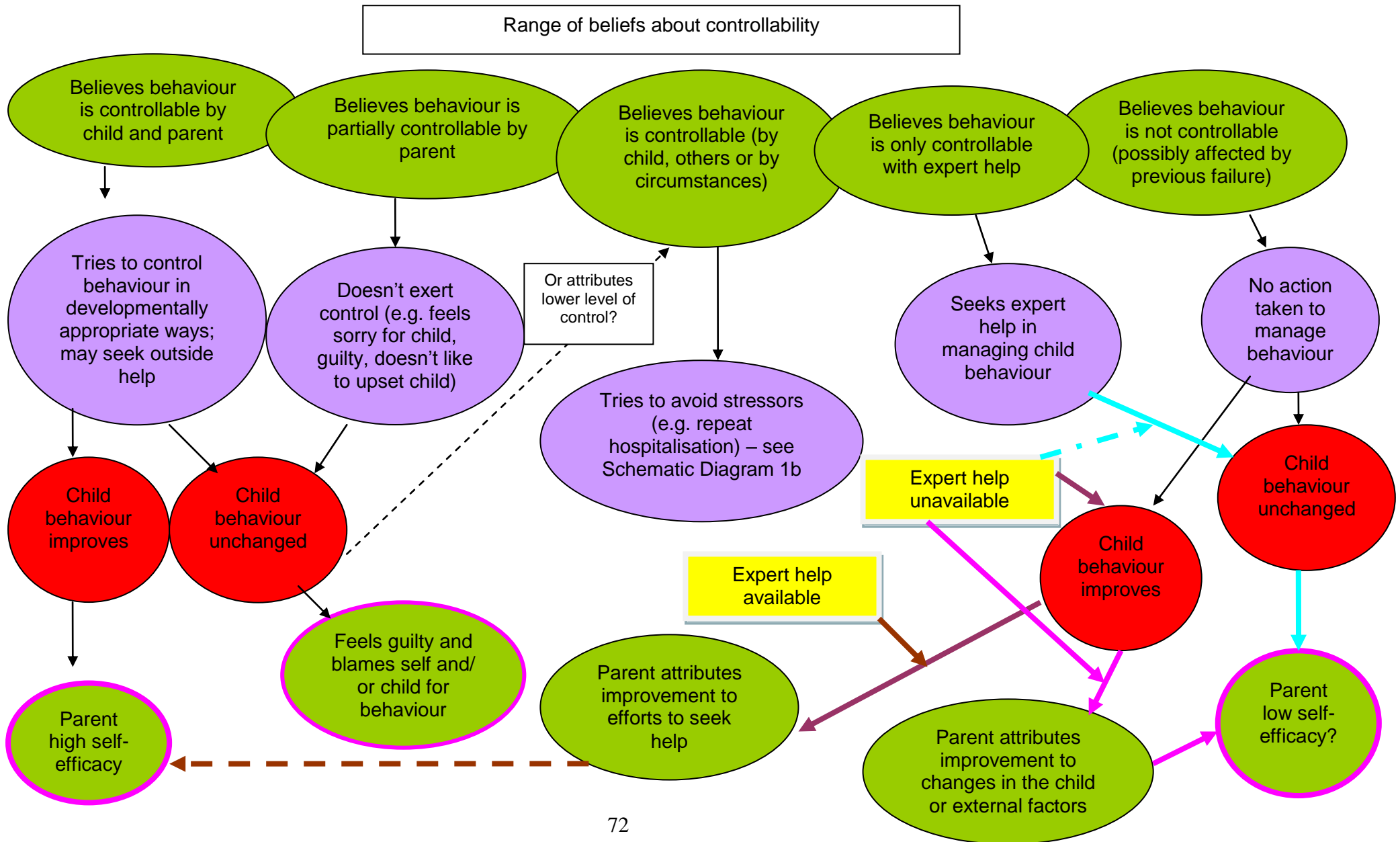
Appendix 4.11: Schematic Diagram 5: Disease / treatment-related behaviour – Asthma Group (child has poorly controlled asthma and is 'sporty').



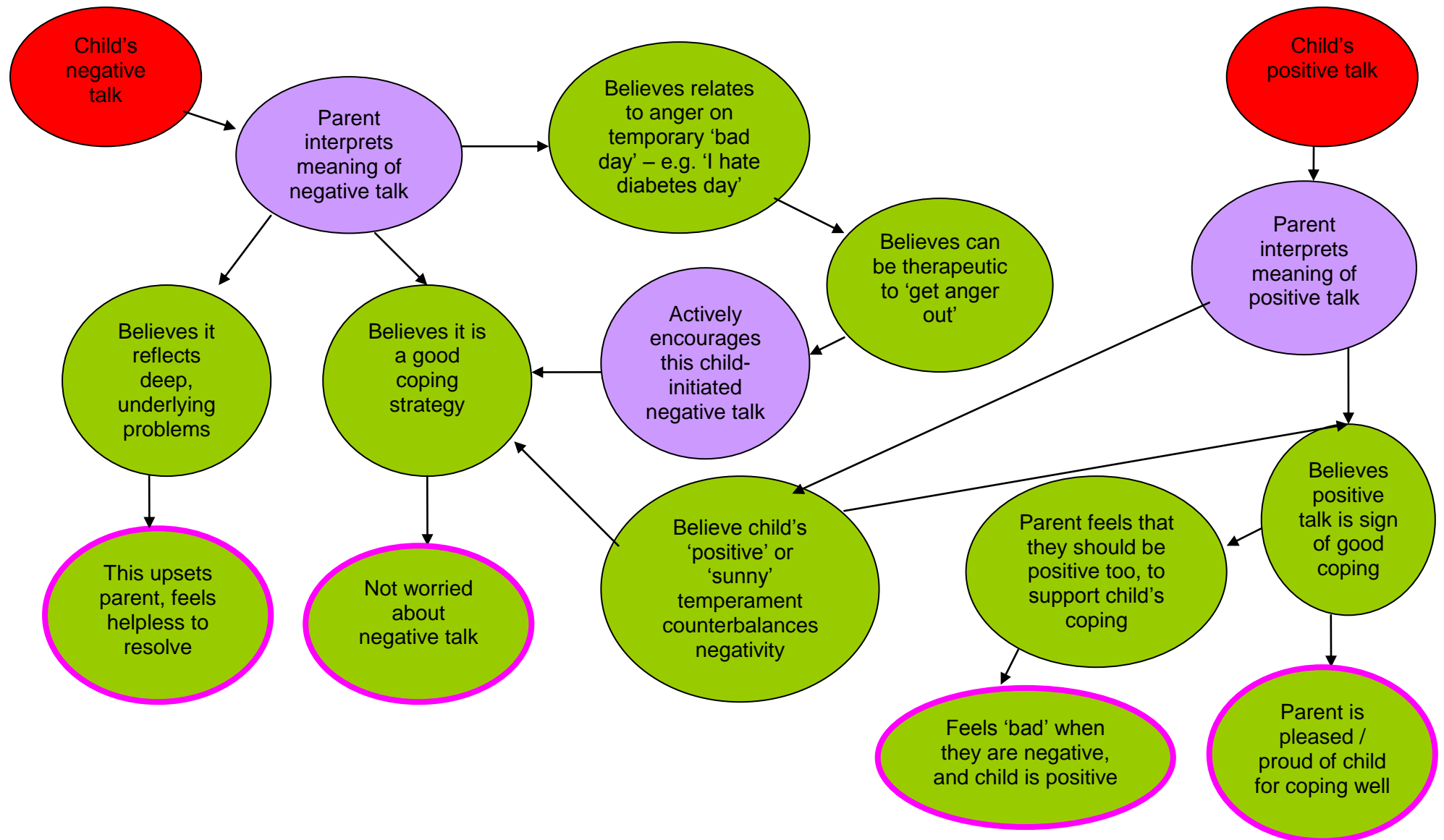
Appendix 4.12: Schematic Diagram 6a: Internalising and externalising behaviour – Both Asthma and Diabetes Groups



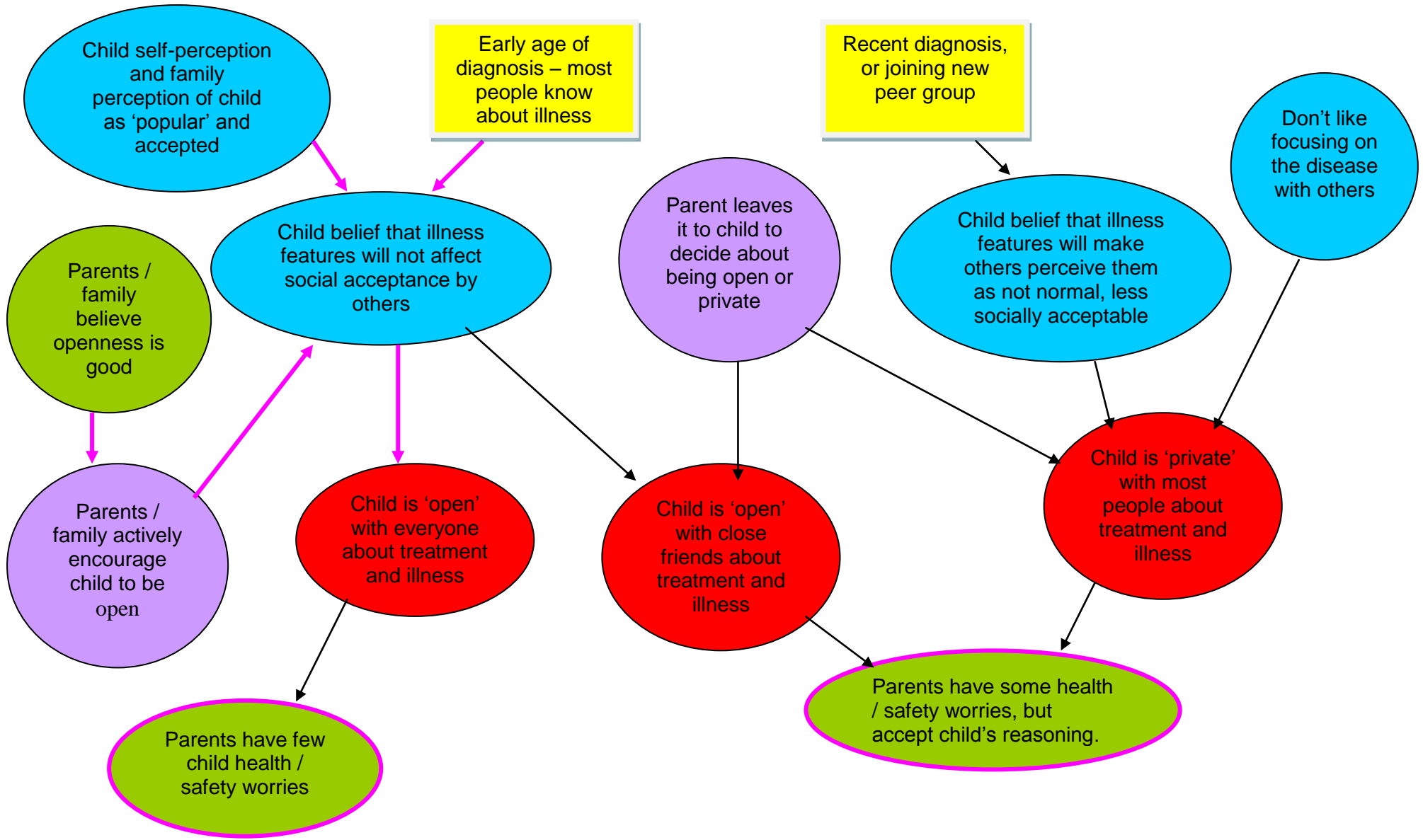
Appendix 4.12: Schematic Diagram 6b: Internalising and externalising behaviour – Both Asthma and Diabetes Groups



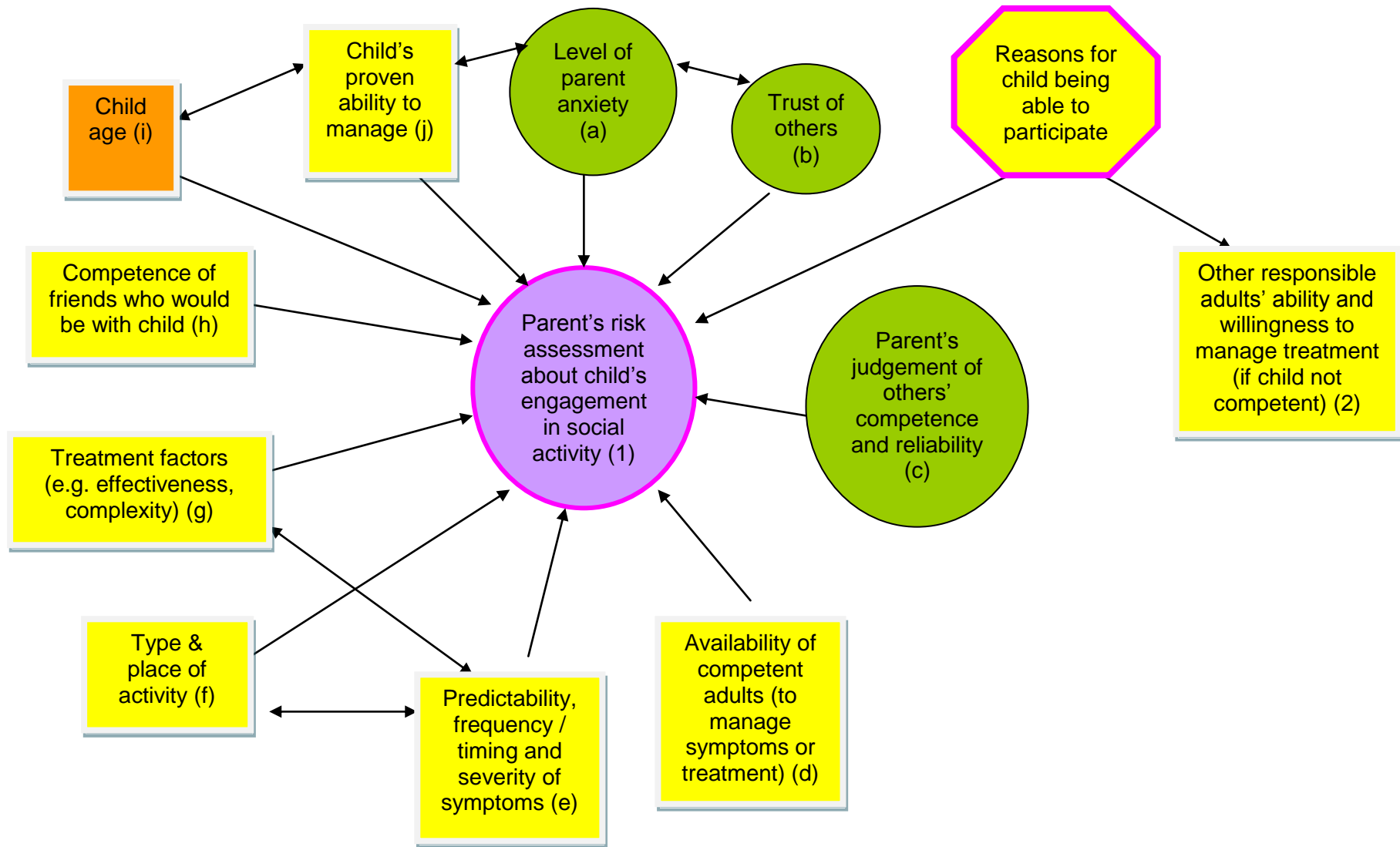
Appendix 4.13: Schematic Diagram 7: – Positive and negative talk - Both Asthma and Diabetes Groups



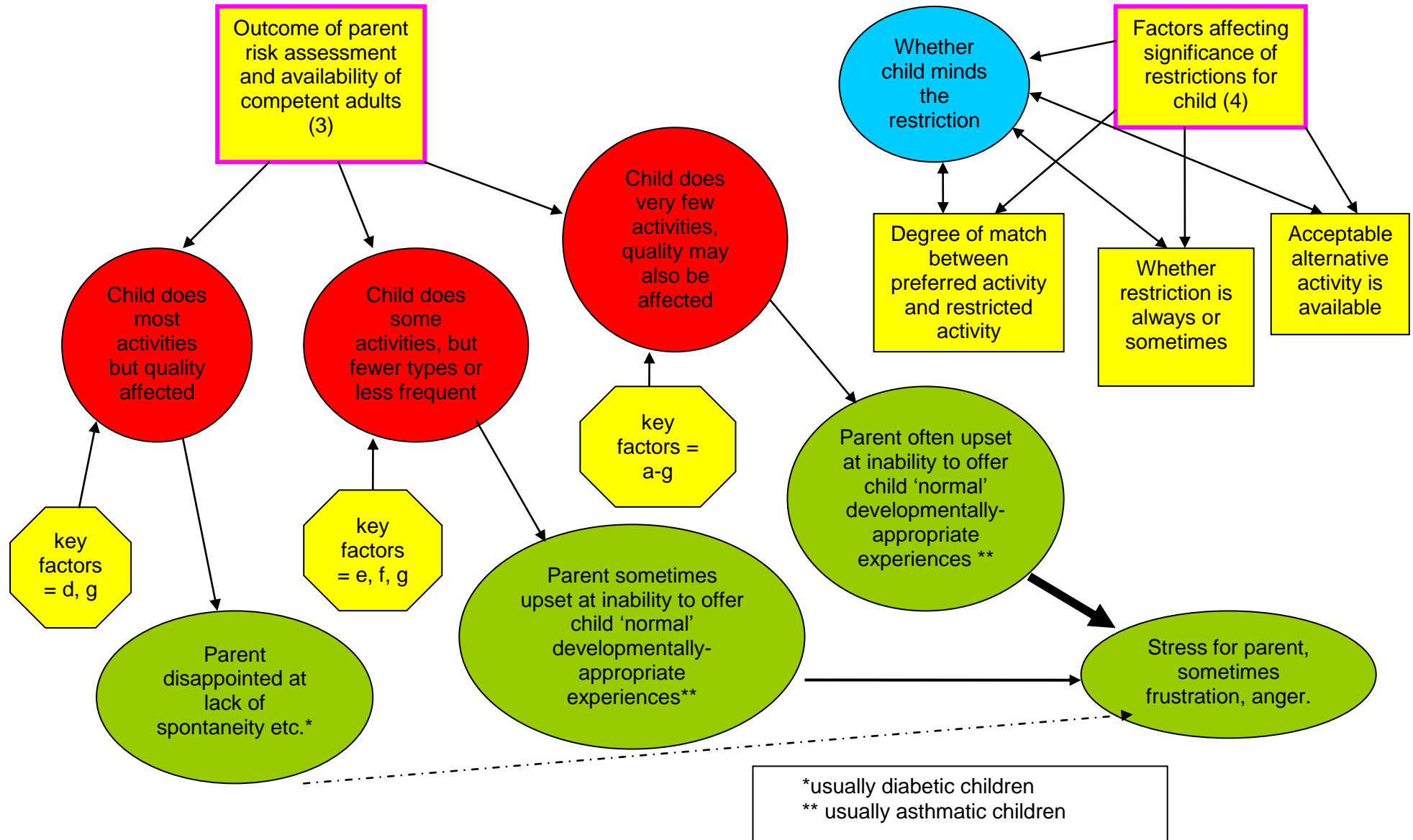
Appendix 4.14: Schematic Diagram 8: Being open and private - Both Asthma and Diabetes Groups



Appendix 4.15: Schematic Diagram 9a: Effects on Child’s Social Life – Reasons for Child not participating in Activities – Both Asthma and Diabetes Groups



Appendix 4.16: Schematic Diagram 9b: Effects on child's social life: Outcome of parents' risk assessment – Both Asthma and Diabetes Groups



APPENDIX 5.1: ASTHMA GROUP: Individuality of Response: Physical responses and triggers
All children (aged 2 – 16)

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Physical response or trigger component</i>																
triggers always known	√	√		√	√				√	√	√ (A)			√		√
triggers sometimes known			√			√	√	√			√ (E)	√	?		√	
symptoms of attack always recognised by parent and/or child	√	√		√	√	√	√	√		√		√		√	√	√
symptoms of attack sometimes recognised by parent and / or child			√						√				?			
side effects or other disease effects recognised	√	√ (*)		√	√	√			√	√		√				√
side effects or other disease effects not known or not reported		√ (*)	√				√	√			√		√	√	√	
medication always works	√ (E)									√						
medications sometimes or usually work	√ (A)	√			√	√		√	√						√	√
symptoms / disease course always predictable										√				√		
symptoms / disease course sometimes unpredictable		√				√		√	√	√					√	
symptoms / disease course unpredictable	√		√		√							√				√ (E)

E=eczema; A=asthma; *=partial; **=child had recent unusual and unexpected, life-threatening attack

Shaded columns represent non-clinic respondents

APPENDIX 5.2: ASTHMA GROUP: Managing Treatment – Children aged 8 years or under

Child age (years)	2	4	4	5	7	8
Participant number	A_13	A_2	A_16	A_7	A_11	A_12
‘Parent control’ group: Parent takes control of treatment management (n=1)						
Parent has full control of treatment	√					
Child cooperates with treatment	√					
‘Limited shared control’ group: Parent has control but child <u>sometimes</u> indicates when medication is needed and <u>sometimes</u> participates in self-medication (n=2)						
Parent lacks confidence that child has taken medication independently; child needs frequent reminders; parent has to check that sufficient medication is available		√		√		
Cooperation is variable; possibly forgets or may take medication inappropriately due to misunderstanding		√		√		
‘Some shared control’ group: Parent has control but child <u>normally</u> indicates when medication is needed and <u>normally</u> participates in self-medication (n=2)						
Parent controls routines and sometimes prompts child to take medication			√		√	
Good cooperation			√		√	
‘Effective shared control’ group: Control is effectively shared between child and parent (n=1)						
Child nearly always remembers to take medication, but might need occasional reminder; parent shows firmness and reasoning if reluctant						√
Good cooperation (but problems of control despite precautions)						√

*N.B. ‘Effective shared control’ refers to when the child will always or nearly always take medication or follow treatment themselves and/or reliably indicate to an adult when medication or treatment is needed.

APPENDIX 5.3: ASTHMA GROUP: Managing Treatment – Children aged over 8 years

Child age (years)	10	10	11	12	13	13	14	15	16	16
Participant number	A_1	A_9	A_10	A_8	A_6	A_15	A_4	A_5	A_3	A_14
‘Limited shared control’ group: Parent has control but child <u>sometimes</u> indicates when medication is needed and <u>sometimes</u> participates in self-medication (n=4)			√	√		√		√		
Parent lacks confidence that child has taken medication independently; child needs frequent reminders; parent has to check that sufficient medication is available			√	√		√		√		
Cooperation is variable; possibly forgets or may take medication inappropriately due to misunderstanding			√	√		√		√		
‘Some shared control’ group: Parent has control but child <u>normally</u> indicates when medication is needed and <u>normally</u> participates in self-medication (n=3)	√	√								√
Parent controls routines and sometimes prompts child to take medication	√	√								√
Good cooperation; occasionally doesn’t take preventer, in one case reported reason was not to appear different to peers	√	√								√
‘Effective shared control’ group: Child mainly takes control of treatment management, but parent monitors and intervenes as needed (n=3)					√		√		√	
Parent ‘keeps an eye’ and may check if child has taken medication					√		√		√	
Child cooperates with treatment; tells parent if insufficient medication is available					√		√		√	

APPENDIX 5.4: DIABETES GROUP: Individuality of Response: Physical responses and triggers
All children (aged 8 – 16)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Physical response or trigger component</i>																
<i>General health</i>																
When she overdoes it physically, she gets ill more than other people do													√			
He's rather small, but catching up											√					
<i>Not recognising onset of hypos or hypers</i>																
Sometimes doesn't recognise symptoms predicting onset of hypos or hypers									√					√	√	
<i>Recognising response to onset of hypos or hypers</i>																
Doesn't do what he's told when having a hypo							√									
Tends to get sleepy when having a hypo							√									
Can get angry and walk out of situation when hypo							√									
Tends not to think clearly when having a hypo		√					√									
Gets shaky when hypo													√			
Previous tendency to go very pale with hypo		√														
Eyes dilated, surrounded by white		√														
Says feels sick when has a hypo	√	√														
Sits up in bed, talks nonsense, has nightmares when hypo						√										
Has glazed look, stares when has hypo						√										
Has angry, screaming fits when has a hypo														√		
Gets bad tempered when going hypo or hyper				√												

Appendix 5.4 (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Physical response or trigger component</i>																
<i>Child's individual physical response in general is known</i>																
Blood sugars relatively stable; rarely has a hypo								√								
Tends to get a lot of hypos in AM (poor management)		√					√									
Tends to get a lot of hypos (good management)	√					√						√				
Has (or has had) night-time hypos		√		√		√					√	√		√		
Often becomes unconscious in response to hypo	√															
Being an active boy, his blood sugars are too high if on a plane (inactivity)										√						
When on holiday, his blood sugars are more stable as he is more active				√												
Not eating enough appropriate food means she has to take more insulin														√		
Blood glucose levels are unstable due to puberty											√		√			
Blood sugars drop 3-4 hours post-injection (earlier than other children)		√														
Blood sugars unstable during insulin dosage changes											√					
When she exercises to lose weight, she gets a hypo, then eats sweets and this makes her put on weight			√													
<i>Child's individual response to a hypo is unexpected or unknown</i>																
Hypos can be unexpected and don't correspond to management & blood sugar readings		√										√				
Usually has shakiness with hypos, but one time had swearing and other uncharacteristic behaviour				√					√							
Had hypo in the morning when she couldn't speak (not usual response)														√		
Unexpectedly went unconscious, and started fitting when hypo				√								√				
Strange, silly behaviour (only known hypo episode)										√						

**APPENDIX 5.5: DIABETES GROUP: Managing Treatment
Children aged 8 years or under**

Child age (years)	6	8	8	8
Participant number	D_4	D_2	D_6	D_15
‘Limited shared control’ group: Parent has control but child <u>sometimes</u> takes control of some aspects of treatment management, and this is <u>not</u> well-managed.				√
Parent decides when child will have injections and gives injections but often child chooses site (inappropriately)				√
Child does blood tests, but uses same two fingers (inappropriately)				√
Parent doesn’t have confidence that child would behave responsibly (e.g. not eat sweets)				√
‘Some shared control’ group: Parent has control but child <u>sometimes</u> takes control of some aspects of treatment management, and this <u>is</u> generally well-managed				
Parent gives injection	√		√	
Parent normally tests child’s blood sugar (but child has done occasionally)	√		?	
Child generally chooses his meals in discussion with parent	√			
Parent expects child to behave responsibly (e.g. if has hypo, will take glucose tablet)	√			
Remembers to take medication and glucose tablet / cereal bar when at school or out and about	√			
Parent doesn’t have full confidence that child will be truthful about meals, snacks etc.	√			
Parent normally decides what child eats.			√	
‘Effective shared control’ group: Child <u>normally</u> takes control of some aspects of treatment management, and this <u>is</u> generally well-managed				
Child gives her own injections		√		
Child tests own blood sugars		√		
Parent has confidence that child would not lie about anything to do with treatment		√		

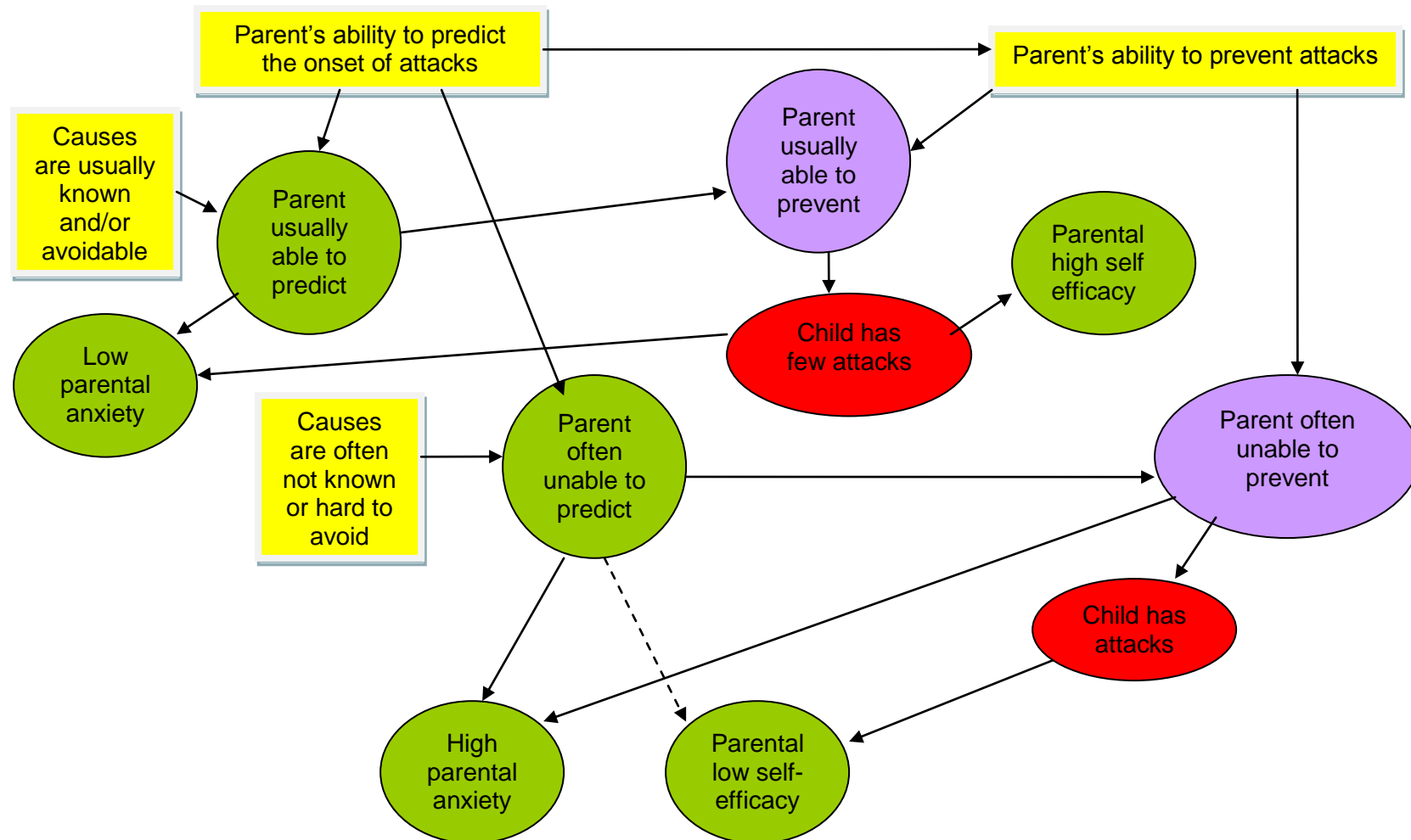
APPENDIX 5.6: DIABETES GROUP: Managing Treatment – Children aged over 8 years

Child age (years)	9	10	10	12	13	13	13	15	15	16	16	16
Participant number	D_1	D_5	D_12	D_13	D_3	D_8	D_14	D_7	D_11	D_9	D_10	D_16
'Limited shared control' group: Child <u>sometimes</u> takes control of <i>some</i> aspects of treatment management, but parent has serious concerns about management							√	√				
Child can't be relied upon; doesn't do injections at regular time of day								√				
Child does own injections, but needs more of them because she doesn't eat appropriately							√					
Child needs reminding about when insulin dosage needs adjusting, e.g. PE							√					
Nearly always injects in the same place								√				
Parent has to keep reminding child to do his injections – he forgets								√				
Even when reminded by parent, doesn't necessarily do injection								√				
Parent has to constantly nag about doing blood sugars								√				
Child doesn't do enough blood sugar tests							√	√				
When child tests blood sugars, tends to be same two fingers								√				
Child eats what s/he wants, including sweets when inappropriate to do so							√	√				
Child doesn't always tell parent about what high calorie drink she's had and sometimes tests friends' blood sugars so readings are normal on meter							√					

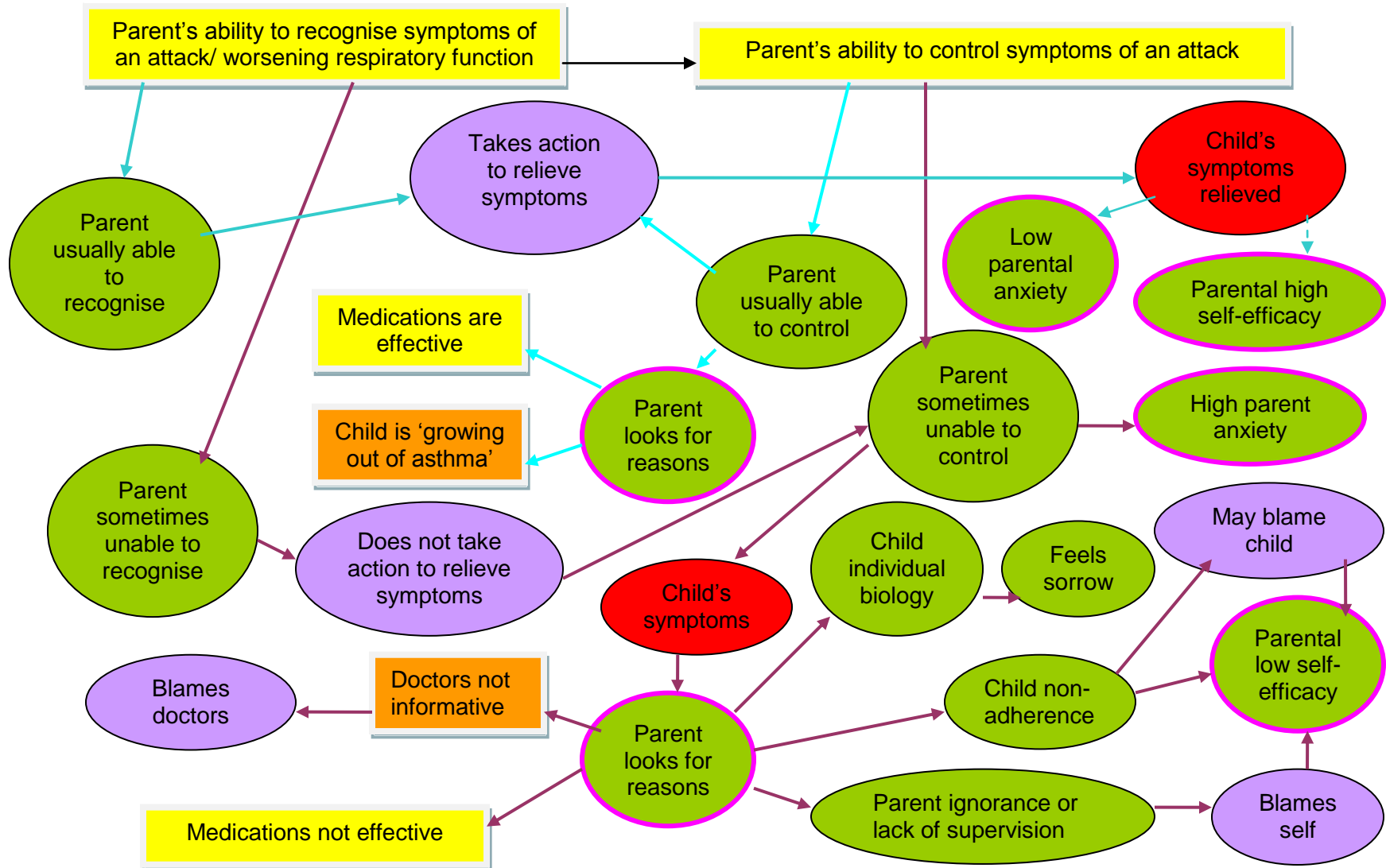
Appendix 5.6 (continued)

Child age (years)	9	10	10	12	13	13	13	15	15	16	16	16
Participant number	D_1	D_5	D_12	D_13	D_3	D_8	D_14	D_7	D_11	D_9	D_10	D_16
‘Some shared control’ group: Child <u>normally</u> takes control of <i>some</i> aspects of treatment management, but parent has <u>some concerns</u> about management				√		√			√		√	
Child usually does own blood sugars and injections, but parent needs to check that s/he’s done this or ‘badger’ them to do them				√		√			√	√	√	
Not always willing to eat, inject and/or do blood sugars when meant to				√		√			√			
Child usually rotates injection sites but sometimes over-uses them						√				√	√	
Doesn’t consistently tell parent if s/he’s eaten or injected without their knowledge (e.g. chocolate)						√					√	
Not always truthful about management issues (e.g. blood sugar readings e.g. if high)						√			√	√	√	
Parent chooses foods she knows child will like at home, but child eats what s/he likes when away from home						√					√	
Knows how to manage hypos (low BS) or hypers (high BS) without help						√			√	√		
Normally eats appropriate foods										√		
‘Effective shared control’ group: Child <u>normally</u> takes control of <i>some</i> aspects of treatment management, and parent has <u>limited</u> concerns about management		√	√									√
Parent gives all the injections (as child has needle-phobia)	√											
Child chooses injection sites and gives them (but may tend to avoid one area)		√	√									√
With help of an alarm, reliably takes his snacks		√										
Child does blood sugars (but may need help interpreting results)	√		√									√
Doesn’t eat sweets when he knows he shouldn’t	√	√										
Can trust to take responsibility for self-care (even when adults give incorrect advice)	√	√	√									
Sometimes needs reminding about doing blood tests			√									√

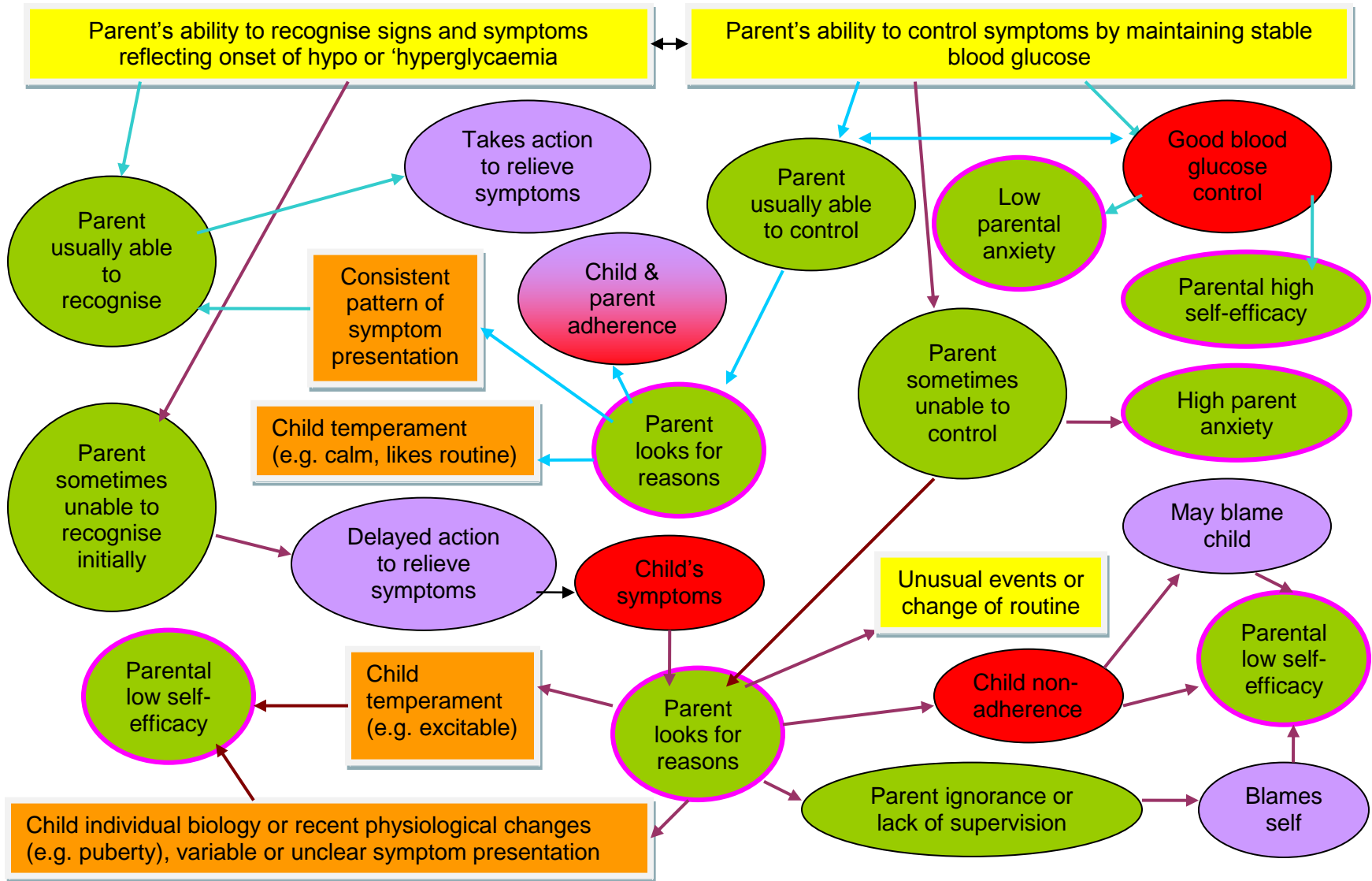
Appendix 5.7: Schematic Diagram 10: Parent efficacy of prediction and prevention of symptoms – both illness groups but more typical in Asthma Group



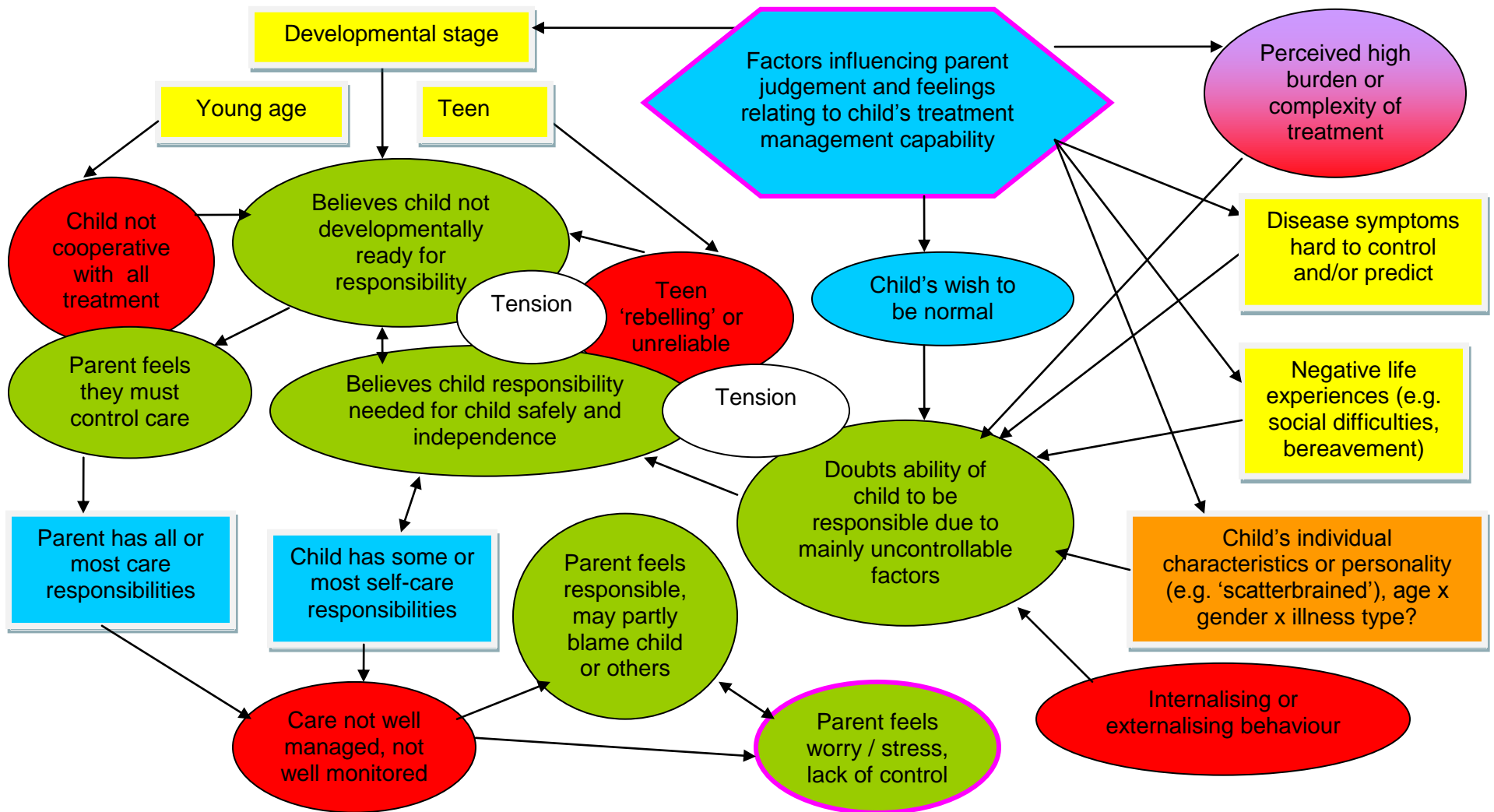
Appendix 5.8: Schematic diagram 11: Parent efficacy in symptom recognition and control – Asthma Group



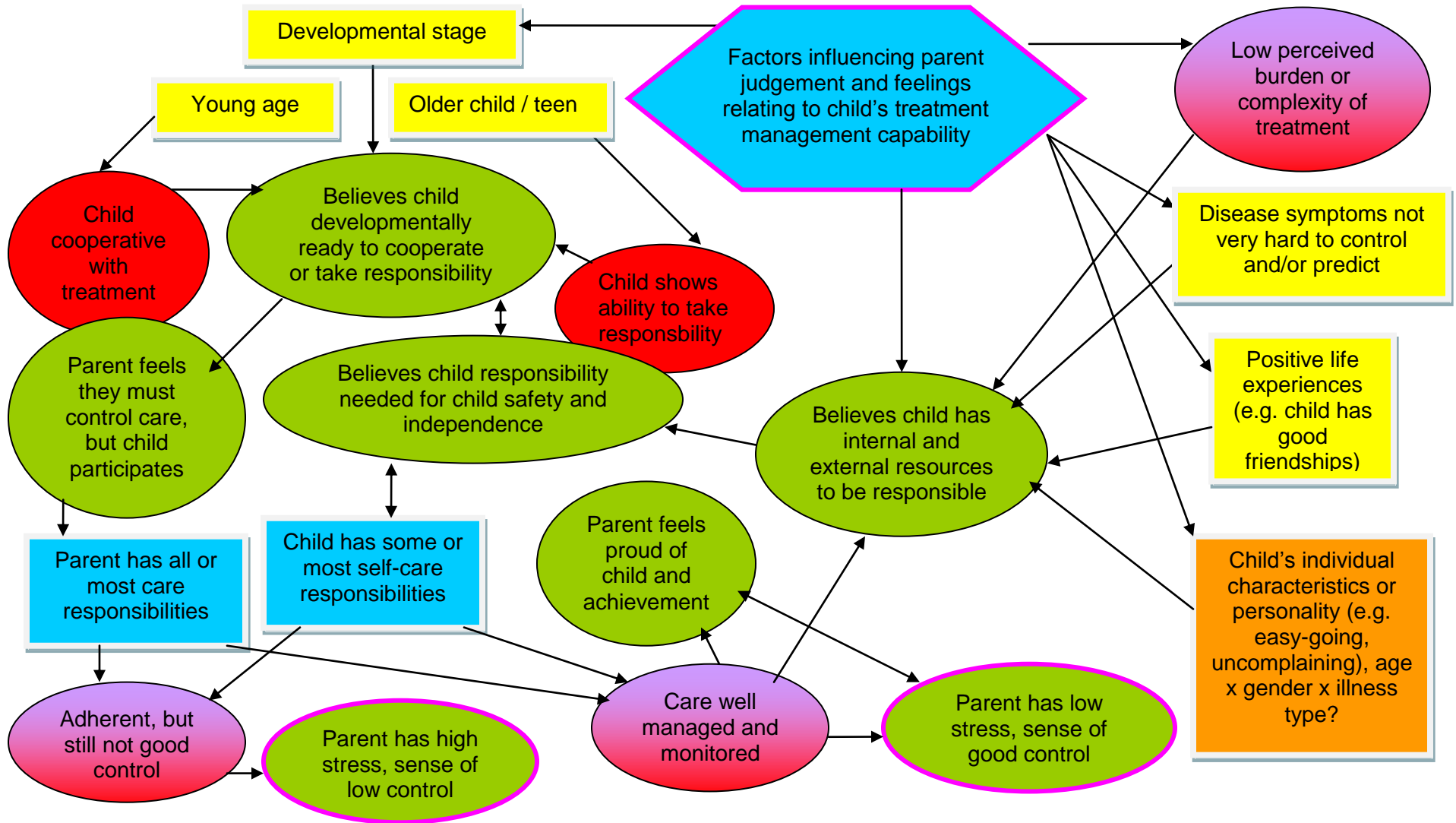
Appendix 5.9: Schematic Diagram 12: Parent efficacy of symptom recognition and blood glucose control – Diabetes Group



Appendix 5.10: Schematic Diagram 13: Parents' judgment and emotions about sub-optimal adherence by child in treatment management – both illness groups

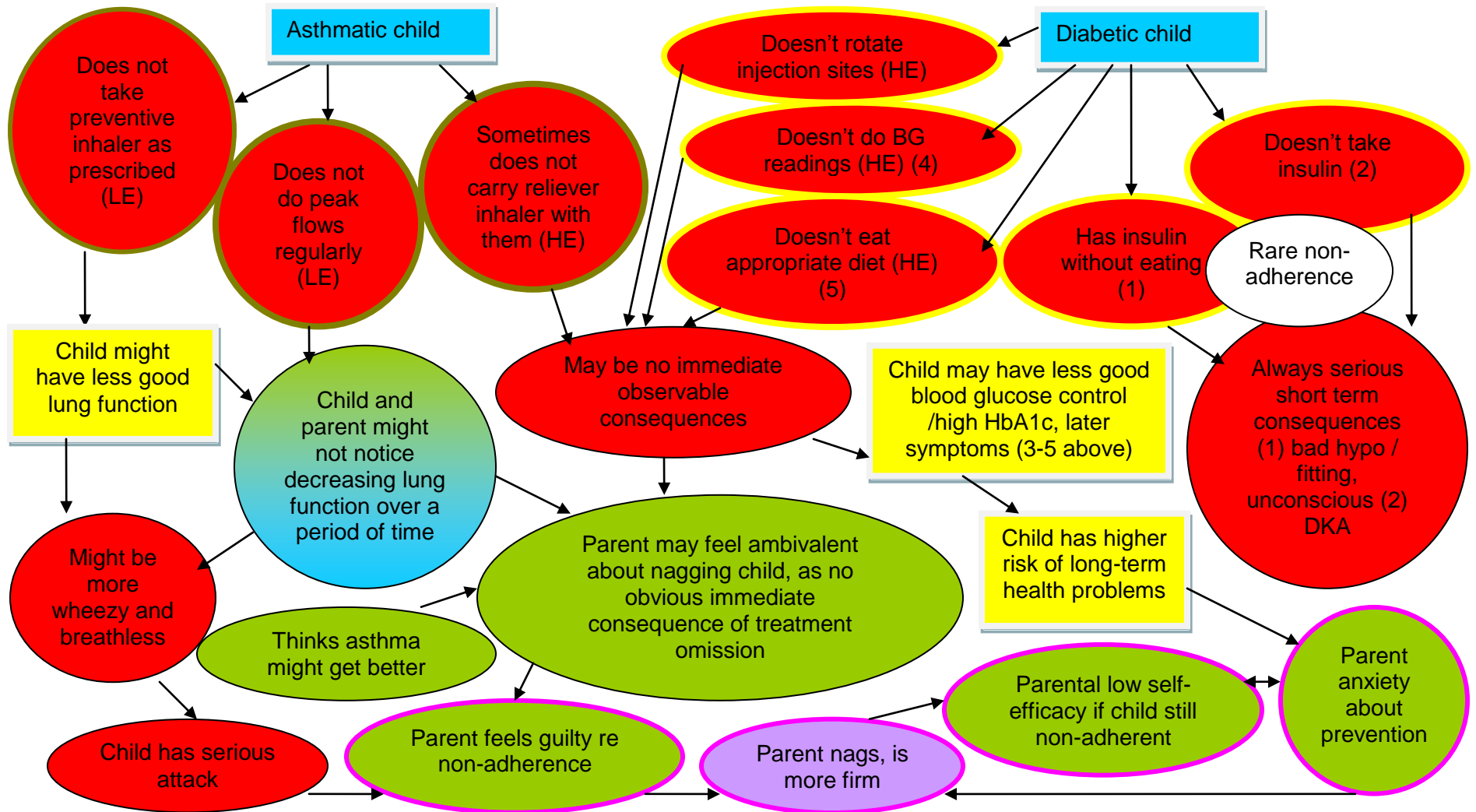


Appendix 5.11: Schematic Diagram 14: Parents' judgment and emotions about good compliance of child in treatment management – both illness groups



Appendix 5.12: Schematic Diagram 15: Disease-specific differences in consequences of poor adherence, and significance for parents' adjustment

(L.E. = low demand/effort, e.g. only remember daily, and/or not hard to do; H.E. = high demand/effort, e.g. remember always and/or hard to do)



APPENDIX 6.1: ASTHMA GROUP: Personal History with the Disease

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
Family history and impact																
<i>1) Reports that no known family history</i>			<													
<i>2) Family history of eczema only</i>										✓						
Impact of family history																
Beliefs																
'No rhyme or reason' – was breast fed and parents non-smokers										✓						
<i>3) Family history of asthma in one or both parents, or in sibling(s)</i>	✓	✓					✓		✓		✓	✓		✓	✓	
Child's symptoms or course are similar to parent's or sibling's		✓									✓					
Child's symptoms or course are more severe than parent's or sibling's	✓											✓		✓	✓	
Mixture – some relatives' asthma similar, some less severe							✓		✓							
Impact of family history																
Beliefs																
Belief that boys are affected differently by asthma than girls												✓				
Beliefs that child will 'grow out of it'											✓					
Anticipated child would get asthma							✓									

APPENDIX 6.1 (continued)

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
Knowledge and Skills																
Parent recognises symptoms quickly and can respond appropriately		✓														
Personal experience enables parent to keep calm in emergency		✓												✓		
Felt poor understanding of asthma variations (i.e. can die from it)															✓	
Unexpected severity, but 'knew how serious it could be'									✓							
Attitudes / emotions																
Parent being asthmatic influenced her 'lets get on with it' attitude	✓															
Father knows how to cope due to personal knowledge of own asthma		✓														
Felt shocked at severity																✓
Able to empathise with child more							✓									
Worries more about child due to life threatening asthma of parent's mother							✓									

APPENDIX 6.2: DIABETES GROUP: Personal History with the Disease

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
Family history and impact																
<i>1) Reports that no known family history</i>	√				√			√					√			
Impact of diagnosis when no family history																
Beliefs																
Not having diabetes in family meant family and friends not knowledgeable	√				√			√								
Spent time searching to see if there was a family history, as expected genetic link	√							√					√			
Knowledge and skills																
Perceive that others think it is inherited									√							
Lack of understanding of cause and risks for child's offspring because there was no family history								√								
Attitudes / emotions																
Felt surprised at diagnosis, as expected it to be inherited	√															
Feels intrigued to try to find an ancestor with diabetes (mother)								√								
Looking for history is looking for someone to blame (but self-defeating?) (father)								√								

APPENDIX 6.2 (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>2) Family history of Type 2 only</i>			√													
Impact of family history																
Beliefs																
Able to recognise early symptoms of the disease			√													
<i>3) Family history of Type 1 and sometimes Type 2</i>				√			√							√		
Impact of family history																
Beliefs																
Perceived relative's diabetes control was easier														√		
Knowledge and skills																
Recognised symptoms prior to diagnosis							√									
Attitude / Emotions																
Feeling of guilt about genetics and bad memories of fathers' illness				√												
Feeling of it not being fair that child got diabetes – denied it initially							√									

APPENDIX 6.3: ASTHMA GROUP: Episodes / typical / knowledge

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Number of episodes described</i>	2	2		1	2			6			2	3		4	5	1
<i>Episode related to preventing attack – no medical intervention</i>	1							3				1				
<i>Episode related to an acute attack or worsening symptoms – sees GP</i>				1							1			1	1*	
<i>Episode related to an acute attack – hospital admission</i>		2			2			1*			1				2	1
<i>Episode related to an acute attack – no medical intervention (i.e. parent manages on own)</i>	1							1*+1				1		1*+	1*	
<i>Episode related to medical intervention (related to other health problem)</i>														1		
<i>Knowledge and beliefs about symptoms, treatment, and causes in relation to episode</i>																
Expresses knowledge about drugs, treatment and / or prevention	√	√			√			√			√	√		√	√	√
Expresses knowledge about child symptoms		√						√				√		√	√	√
Parent believes they can make independent decisions without additional medical advice												√		√	√	
Recognised symptoms or behaviours that were related to onset or recovery from episode												√		√	√	√
Believes cause(s) of episode external or unknown					√			√				√		√		
Believes cause(s) of episode related to child-specific factors					√							√		√		
<i>Knowledge and beliefs relating to risks and consequences of the episode</i>																
Believes hospitalisation is risky due to possibility of acquiring infection there											√					√
Believes episode had negative psychological impact on child																√

APPENDIX 6.3 (continued)

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Actions or behaviours of doctors, the child or other people in relation to the episode</i>																
Believes that doctors trust the parent to act appropriately, but sometimes they wish the doctor would make the decision for them				√												
Believes that doctors do not provide enough information about dosage for inhalers																√
Believes doctors do not always know what is best for the child and should appreciate parents' experience and knowledge more					√			√						√	√	
Believes that certain doctors are very competent, and you have to trust them															√	
Believes parent is sometimes more competent than doctors (esp. GPs) in child assessment and / or treatment choice		√			√									√	√	
Believes that sometimes you just have to be assertive with doctors or make up your own mind								√						√		
Believes others (teacher, other parent) are irresponsible or lack knowledge, putting child at risk	√							√								
Believes child sometimes hides information from parent					√											
Believes child is not developmentally ready to take responsibility and/or behave cooperatively		√						√								
Believes child had appropriate responses in risky situations (can weigh up risks)								√								

APPENDIX 6.4: ASTHMA GROUP: Episodes / typical / feelings

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Number of episodes described</i>		1		1	2			3			2	1		3	4	1
Episode related to preventing attack – no medical intervention								3								
Episode related to an acute attack or worsening symptoms – sees GP				1							1			1	1*	
Episode related to an acute attack – hospital admission		1			1						1				2	1
Episode related to an acute attack – no medical intervention (i.e. parent manages on own)					1*							1		1*+ 1	1*	
<i>Worry, distress and anxious behaviours</i>																
Onset of attacks are frightening											√	√				
Feels panicky when asthma out of control											√			√		
Worry that child might need to go to hospital, because of infection risks there										√						√
When in hospital, feels compelled to count respirations more frequently than advised																√
Feels anxious about making own decision about drug dosage																√
Worries that child not assertive in risky situations								√(M)								
Tries not to let child see parent anxiety		√						√(M)								
Feels unable to cope with stress of risky situation								√(M)								
Feels anxiety, but able to control feelings								√(F)								
Worry about knock-on effects of repeated attacks				√												
Felt stressed at difficulties of not being able to get medical attention in time (and sometimes not being understood due to language barrier)				√							√			√		

APPENDIX 6.4 (continued)

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Worry, distress and anxious behaviours (continued)</i>																
Feels burden of responsibility sometimes				✓												
Wants doctors to make decisions sometimes; feels anxious about taking decision about whether child should be hospitalised				✓												
Has experienced distress when child in hospital (e.g. related to child having needles)		✓													✓	
<i>Frustration, annoyance or anger</i>																
Feels frustrated that that doctors don't give enough info re drug dosage (left in 'limbo')																✓
Feels frustrated at inconsistency of advice between GP and hospital doctors																✓
Annoyed at doctors for not focusing on immediate problem of treating illness or when doctor disagrees with parent view on treatment					✓						✓			✓	✓	
Felt experience not respected by doctors														✓	✓	
Feels frustrated by insurance companies who won't insure child for asthma care on holiday														✓		
<i>Sadness and disappointment</i>																
Feels sad and sorry for a chronically sick child who's always there when they go to hospital																✓
Feels sad that her child has to cope with disappointment at not being able to do things								✓(M)								
Feels sad at what child had to endure in hospital															✓	
Feels low, lacking in self-confidence and self-esteem (when asthma control was poor)				✓												
Feels disappointed that has no other parent to talk to who has similar experience		✓														
Feels unsupported by hospital (in coping)		✓														

APPENDIX 6.4 (continued)

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Discomfort</i>																
Disliked sleeping in uncomfortable hospital beds and early morning waking (for medications)															√	
Disliked using hospital showers																√
Night-times awful / horrible (disturbing)														√		
<i>Positive and neutral feelings</i>																
Feels pleased that child can express feelings about disappointments								√(F)								
Reminds self that other children are worse off																√
Feels able to help when ‘playing down’ and normalising hospital experience for child															√	
Feels better (less distress) when can talk about feelings to own mother		√														
Doesn’t usually worry as attacks and management are routine; usually feels confident					√									√		
When able to calm child down during attack, felt positive.														√		
Felt relieved after the episode, that it was over											√					
Thankful that child’s health improved, so fewer hospital stays needed															√	
Pleased that grandmother able to support child when having injections (as mother too anxious)															√	

APPENDIX 6.5: DIABETES GROUP: Episodes / typical / knowledge

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
Number of episodes described	2		1	1		1	1		1	3			1	6		1
Acute attack (hypo or hyperglycaemia)	1* + 1*		1*	1*		1*	1		1	1*			1*	4 + 2*	1*	1*
Acute episode unrelated to diabetes										2						
Knowledge and beliefs about symptoms, treatment, and causes in relation to episode																
Expresses knowledge about drugs, treatment and / or prevention			√	√		√	√			√			√	√	√	√
Expresses knowledge about child symptoms				√		√	√			√			√	√	√	√
Don't know how to get blood sugars 'average'																√
Knows when to take child to hospital and when this isn't necessary – based on symptoms														√		
Don't know how they're doing with BG control, because they have no comparison													√			
Believes parents are lucky child has few hypos													√			
Believes that not child not being admitted to hospital is a good indicator of 'doing alright'													√			
Believes having frequent hypos at school is bad for child health and development	√															
Parent believes they can make independent decisions without additional medical advice				√						√				√		
Parents believe they have tried everything to manage or prevent future episodes	√													√		
Parents believe all parents experience difficult / angry child behaviour														√		
Recognised symptoms or behaviours that were related to onset or recovery from episode				√			√						√	√		√
Believes cause(s) of episode external or unknown			√													

APPENDIX 6.5 (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
Believes cause(s) of episode related to child-specific factors			√				√							√		
Believes avoidance of or occurrence of episode(s) related to parent's behaviour						√							√			
<i>Knowledge and beliefs relating to risks and consequences relating to the episode – changed perspectives</i>																
Always waiting for another adverse event										√						
Having diabetes makes child have more than his fair share of other health problems										√						
Believes child hospitalisation is bad for sibling, as it is disruptive.															√	
Feels outcome of episode was greater learning (more relaxed about using Hypostop)			√													
Would go on holiday now (immediately after episode) more readily than previously														√		
<i>Actions or behaviours of doctors, the child or other people in relation to the episode</i>																
Doubts accuracy of doctor's information										√						
Believes that doctors do not provide enough information about health problems, symptoms, risks and / or recovery phase										√				√		
Believes doctors have it easier than parents with regard to managing hypo episodes														√		
Believes doctors don't always believe something is serious, when the parent does (misdiagnosis)										√						
Believes that sometimes you just have to be assertive with doctors or make a fuss										√						
Believes others (teacher, other parent, sibling) are irresponsible or lack knowledge	√						√		√							
Believes those who know child well can recognise signs of hypo		√							√							

Appendix 6.5 (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
Believes child recognises and responds to signs of impending hypo attack				√						√			√			√
Believes child does not always recognise when they are having hypo as can't think straight		√														

APPENDIX 6.6: DIABETES GROUP: Episodes / typical / feelings

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Number of episodes described</i>	2		1	1		1			1	2			1	6	1	
Acute attack (hypo or hyperglycaemia)	2		1*	1*		1*			1	1*			1*	4+	1	
Acute episode unrelated to diabetes										1				2*		
<i>Worry, distress and anxious behaviours</i>																
Felt it was awful to force glucose gel into child's mouth during severe hypo				√ (M)												
Too distressed to cope with hypo attack				√ (F)												
Worry about other parts of life (working) makes coping with hypos more stressful				√ (F)												
Worry that in future, child might lose ability to recognise when he's 'low'										√						
Feels more anxious about ordinary health problems, because child is diabetic										√						
Until had the first 'hypo', felt ill at ease, because didn't know what would happen			√													

Appendix 6.6 (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
Worries about who would deal with hypo and look after child, and handing over responsibility			√													
Worries about effect on sibling if child has to be hospitalised															√	
Worries about effect on child's physical and social life of having frequent hypos at school	√															
Feels upset that can't show upset to child (when having needles)	√															
Finds child's response to needles horrible to witness, and freaky	√															
<i>Frustration, annoyance or anger</i>																
Angry or annoyed at some teachers for not preventing hypo or not responding to one.	√		√						√					√		
Annoyed at self if child goes hypo, as parent believes it's her fault				√												
Sometimes annoyed at lack of understanding by teachers or doctors									√					√		
Anger or annoyance at child for not preventing hypo or withholding information				√										√		
Frustration at lack of success in persuading child to be compliant														√		
Doctors don't appreciate how hard it is for parents (they only need to put in a drip)														√		
<i>Uncertainty / lack of confidence / helplessness</i>																
Can't handle child's fits because of own problems / other things to do.				√ (F)												
Feels unable to gain child's cooperation in care – have tried everything														√		
Feels clinic staff more competent than parent at calming child when having needles	√															

Appendix 6.6 (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
Feels can't be critical of school for not giving proper medical care, as it would alienate them														√		
Unsure how to respond to child letting herself go hypo														√		
<i>Confidence / being positive</i>																
Parent confident at present about recognising and managing hypos at night										√						
Feels they must be doing something right, as child has not been hospitalised													√		√	
After feeling angry, was able to see the positive side of the episode			√													
Accepts own feelings of initial anger at teachers; it was necessary to experience it			√													
Feels positive about teachers, who are supportive with child's condition			√													
Having frequent hypos / hospital admissions means confident to go on holiday afterwards (callous indifference?)														√		
Reminds self that situation could have been worse														√		
Avoids worry of 'hype' of hospitalisation by avoiding this where possible														√		
Feels proud that child is brave when having needles, and that he is accepting of diabetes	√															
Accepts that one can't expect teachers to know as much as child or family			√													
Accepts child will need to express anger														√		
Feels that other parents experience similar problems – it's normal														√		

APPENDIX 6.7: ASTHMA GROUP: Episodes / atypical / knowledge

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
Number of episodes described	1	1	1		1	1	1	2	2		1	3			1	4
<i>Acute attack involving hospital admission</i>	1		1			1	1	2	1		1	3			1	
<i>Medication administration issue</i>					1											1
<i>Encounters with doctors (for asthma or eczema)</i>									1							3
<i>Acute illness episode (febrile convulsions)</i>		1														
Knowledge and beliefs about symptoms and treatment and causes in relation to episode																
<i>Not time-linked</i>																
Expresses knowledge about drugs and treatment		√	√		√	√	√		√			√				√
Expresses knowledge about child symptoms	√	√	√		√	√	√		√		√	√				√
<i>Initial knowledge or beliefs</i>																
Recognised symptoms or behaviours that were related to onset or recovery from episode	√	√			√	√					√	√				√
Did not recognise symptoms or behaviours that were related to (predictors of) onset of episode			√				√		√							
Knowing child helped identify onset of episode	√											√				
'Intuition' helped identify onset of episode												√				
<i>Intermediate or later knowledge or beliefs (specific to time of episode)</i>																
Believes episode cause(s) external or unknown						√					√	√				√
Believes episode cause(s) related to lack of parental knowledge			√				√		√							
Believes episode cause(s) child-specific	√				√											
<i>After episode – new knowledge or beliefs</i>																
Acknowledged new knowledge from episode			√				√		√			√				
Makes independent decisions without advice							√									√
Learning from episode helped predict problems and / or changed future behaviour			√				√		√						√	
Realised later that hadn't appreciated seriousness of episode (e.g. 'could have died')			√					√	√							

APPENDIX 6.7 (continued)

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Actions or behaviours of doctors in relation to the episode</i>																
<i>After episode – new knowledge or beliefs</i>																
Doctors appreciate that parent responds correctly												✓				✓
Doctors don't always know what is best for the child – may not appreciate urgency or don't agree with parent view	✓						✓	✓	✓			✓				✓
Doctors can't answer all the parents' questions																✓
Doctors who listen to you are good, and doctors who patronise you aren't.																✓

APPENDIX 6.8: ASTHMA GROUP: Episodes / atypical / feelings

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
Number of episodes described	1		1			1	1	2	2		1	3			1	
<i>Acute attack involving hospital admission</i>	1		1			1	1	2	1		1	3			1	
<i>First encounter with respiratory clinic</i>									1							
Worry, distress or anxious behaviours																
<i>Initial responses</i>																
Panic / extreme fear – maybe shouting								√			√	√				√
Fear of child’s possible death											√	√				
Shock at how ill child was			√						√							
Blocking feelings to enable coping						√		√								
Feelings of lack of control or competence											√	√				
Feelings of doubt about whether attack will develop into something life-threatening or not								√								
Displacement? Humour? (Parent thought it was ‘funny’ that doctor didn’t know she knew what it meant when he called for ‘crash cart’ – to prepare to resuscitate child)	√															
<i>Intermediate and later responses (specific to time of episode)</i>																
Worry about effects on child, friends or family							√					√				
Needing to express anxious feelings (but some barriers)												√				
<i>After episode – new worries or anxieties (and associated behaviour)</i>																
Feels more protective towards and closer to child						√						√				
Experience has made parent more anxious – at times, frightened child will die; has nightmares												√				
Thinks about possibility of child dying, but only when child has symptoms.			√													
Recalls previous traumatic episodes; re-experiences ‘traumatic’ feelings												√			√	

APPENDIX 6.8 (continued)

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Worry, distress or anxious behaviours (continued)</i>																
<i>Influences on anxious feelings</i>																
Knowledge as health professional made her fear the worst because she knew what could happen						√										
Tiredness made parent less able to cope												√				
Felt pressure from societal expectations to cope												√				
Other worries (families / work) made the experience more stressful						√	√					√				
<i>Frustration, annoyance or anger</i>																
<i>Intermediate and later responses (specific to time of episode)</i>																
Feeling cross with self / blaming self / guilt			√						√			√				
Blaming GPs/ feeling that GPs not competent									√			√				
<i>Sadness and disappointment</i>																
<i>Intermediate and later responses (specific to time of episode)</i>																
Wished she had known more – preventable?									√							
<i>Positive and neutral feelings</i>																
<i>Initial responses</i>																
Being ‘practical’								√								
<i>Intermediate and later responses (specific to time of episode)</i>																
Feeling secure due to trust in competence of hospital medical and nursing staff									√		√	√				
Keeping positive / positive reconstructions			√									√			√	
Thanks God for child survival/ situation controlled			√								√					
<i>After episode – new positive or neutral feelings</i>																
New learning makes parent more relaxed			√													

APPENDIX 6.9: DIABETES GROUP: Episodes / atypical / knowledge

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Number of episodes described</i>	1	2	2	4	3	2		1	2	1		2			3	
<i>Acute attack (hypo or hyperglycaemia)</i>	1*	2	2	2 + 1*	2 + 1*	2		1	2	1		2			2 +1*	
<i>Other episode (non-urgent)</i>				1												
<i>Knowledge and beliefs about symptoms, treatment and causes in relation to episode</i>																
<i>Not time-linked</i>																
Expresses knowledge about drugs and treatment	√	√	√	√	√	√		√	√	√	√	√			√	
Expresses knowledge about child symptoms	√	√	√	√	√	√		√	√		√	√			√	
Justifies choice of intervention during episode				√				√							√	
<i>Initial knowledge or beliefs</i>																
Recognised symptoms or behaviours that were related to onset of episode	√					√		√							√	
Did not recognise symptoms or behaviours that were related to onset of episode				√	√				√	√	√	√				
'Intuition' helped identify onset of episode or how to respond					√	√										
Knowing child helped identify onset of or reason for episode					√	√									√	
<i>Intermediate or later knowledge or beliefs (specific to time of episode)</i>																
Recognised symptoms or behaviours that were related to recovery from episode															√	
Believes episode cause(s) related to external or unknown factors			√		√				√		√	√				
Believes episode cause related to child-specific factors				√			√		√							
Believes episode cause(s) related to parent's error or limited competence or knowledge		√		√	√					√						
Parent questions if they gave right treatment										√		√				

APPENDIX 6.9 (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Knowledge and beliefs about symptoms, treatment and causes in relation to episode (continued)</i>																
<i>After episode – new knowledge or beliefs</i>																
Acknowledged new knowledge about symptoms, treatment or risks arising from episode					√				√	√					√	
Learning from episode made prediction of problems easier and / or changed parent actual and anticipated behaviours in future					√				√	√					√	
<i>Actions or behaviours of doctors, the child or other people in relation to the episode</i>																
<i>Initial knowledge or beliefs</i>																
Parent believed knew child's needs; Drs. disagreed				√					√			√				
<i>Intermediate or later knowledge or beliefs (specific to time of episode)</i>																
Says hospital information sheet and phone call to doctor enabled her to manage situation		√														
Blames doctors for not warning them this could happen				√												
Believes school staff are poorly informed not to recognise child could go unconscious															√	
Parent tells child of behaviour when unwell (didn't know); believed this was important						√			√							

*'Composite' episodes: e.g. if a parent refers to two or more episodes, referring to similarities between these, these count as one 'composite episode'

APPENDIX 6.10: DIABETES GROUP: Episodes / atypical / feelings

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
Number of episodes described	1	2	2	2	2	2	1	1	2	2	2	3			1	
<i>Acute attack (hypo or hyperglycaemia)</i>	1*	2	2	1	1 + 1*	2	1	1	2	2		2			1	
<i>Other episode (non urgent)</i>				1							2	1				
Worry, distress or anxious behaviours																
<i>Initial responses</i>																
Panic / extreme fear – maybe shouting				√ (M)	√ (M)					√						√
Feels physically ill to stomach (may vomit)					√ (M)				√							
Feelings of lack of control or competence			√	√					√			√				
Fear of child’s possible death					√ (M)							√				√
Fear (controlled, not extreme, but may be crying)	√				√ (F)				√							
Shock or disturbance at unexpected or uncharacteristic reactions of child				√	√ (M)	√				√						
Shock and distress at having to give glucagon, and size of the needle					√											
Feels weight of responsibility (reason for fear)																√
Blocking reality										√						
<i>Intermediate and later responses (at time of episode)</i>																
Worry about effects on child, friends or family			√	√	√	√	√		√			√				
Feels ‘a wreck’ / helpless / exhausted afterwards																√
<i>After episode – new worries or anxieties (and associated behaviour)</i>																
Felt ‘traumatised’ or ‘re-lives’ episode			√	√												
Takes blood glucose kit, snack and glucose with her, even when not with child												√				√
Father tests blood glucose at night; mother ‘over-feeds’ in evening to avoid hypo					√											

APPENDIX 6.10 (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
Worries about child's competence to manage future episode – encourages child's responsibility										√					√	
<i>After episode – new worries or anxieties (and associated behaviour)- continued</i>																
Worry about what might have happened (or could, if there is reoccurrence) – feels insecure					√				√	√		√				
Now worries more about what could happen when out with friends (friends not competent?)										√						
Unwilling to leave child with others post-episode			√							√						
Hopes Drs. will be competent and do the right things (away from own hospital)									√							
<i>Frustration, annoyance or anger</i>																
<i>Initial responses</i>																
Feels angry or annoyed at child							√		√							
<i>Intermediate and later responses (at time of episode)</i>																
Feeling cross with self / blaming self / guilt				√						√		√			√	
Blames child (not caring for self)							√									
Blaming or critical of Drs. (A&E or at different hospital) – affects confidence or security									√		√	√				
Feels annoyed at misunderstanding (negative) of lay witnesses to episode															√	
Feels situation was a disaster				√(F)												
<i>Sadness and disappointment</i>																
<i>After episode – new feelings of disappointment</i>																
Wishing it 'could be easier' – child didn't have diabetes							√				√					
Felt had to give up employment afterwards															√	
Disappointed at effect on social life, as now feels unable to leave child with others			√							√						

APPENDIX 6.10 (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Positive and neutral feelings</i>																
<i>Initial responses</i>																
Feels justified in panic reactions										√						
Being 'practical' / informing others									√						√	
<i>Intermediate and later responses (at time of episode)</i>																
Look at the funny side and laugh about it									√							
<i>After episode – new positive or neutral feelings</i>																
Sometimes feels a bit reassured (as adverse events are rare)										√						
Keeping positive / positive reconstruction of event and consequences			√	√		√										
Feels positive about ability to be advocate for child (but may worry about 'going too far')				√(M)							√				√	
Feeling secure due to trust in competence of hospital medical, nursing or dental staff	√	√	√	√	√											

APPENDIX 6.11 ASTHMA GROUP: Feelings at diagnosis

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Age at diagnosis	2	1	2	<1	1½	2	1	2	1	8	2	2	-	2	1½	2
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Parent observations prior to diagnosis</i>																
Night-time coughs / coughing				√	√	√						√		√		
Night-time wheeze / wheeze	√	√	√				√		√	√	√	√	√	√	√	√
Vomiting feeds				√									√			
Breathless		√			√		√	√	√	√	√			√	√	√
<i>Parent description of kind of onset</i>																
Initial severity of asthma = mild	√		√	√		√			√	√		√	√			
Initial severity of asthma = moderate or severe		√			√		√	√			√			√	√	√
<i>Diagnosis after symptoms</i>																
Recognised early on as asthma	√	√	√	√		√			√	√		√				
Not confirmed as asthma initially								√			√			√		√
Still not confirmed as asthma													√			
Diagnosis confirmed at or shortly after severe attack, soon after symptoms appeared		√			√			√						√	√	
<i>Parent feelings when first appreciating diagnosis</i>																
physical effects																
tired due to disturbed nights				√								√				
anxiety or distress																
shock					√				√						√	√
panic or fear		√								√					√	
upsetting					√		√									√
feeling that it was a tough time					√		√		√							
feeling that child could have died or could die					√			√							√	
evaluation of situation																
bewildered / feeling ignorant													√		√	
relief						√								√		

APPENDIX 6.11: ASTHMA GROUP: Feelings at diagnosis (continued)

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Age at diagnosis	2	1	2	<1	1½	2	1	2	1	8	2	2	-	2	1½	2
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
asking why it happened					✓					✓					✓	
had expected one of children to get asthma, due to family history							✓									
evaluation of situation (continued)																
never thought child would get asthma, even though there is family history		✓							✓						✓	
sadness and disappointment																
disappointed – ‘something else’ (besides eczema)	✓															
feeling unsupported by or not trusting health care professionals									✓							
worry																
worry about child and / or other family members							✓								✓	✓
positive and neutral feelings																
parent took it in their stride / not worried			✓	✓		✓						✓				
hopeful child would outgrow it												✓				
feeling supported by some health care professionals					✓											
<i>Post-initial reactions</i>																
‘Get on with it’					✓				✓							
Dawning realisation of significance / daunting					✓			✓	✓							
Tried to find out triggers					✓					✓					✓	
Did some activity to attempt to improve health or reduce risk					✓			✓		✓					✓	
Determined to avoid future attacks										✓						
Struggled with financial impact					✓											

APPENDIX 6.12 DIABETES GROUP: Feelings at diagnosis

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Age at diagnosis	4	3	11	2	2	2	9	11	8	11	3	5	11	9	3	12
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Parent observations and thoughts prior to diagnosis</i>																
Parent noticed behavioural changes but didn't ever think anything was wrong with child physically										√						√
Parent knew something was wrong with child physically, but not what – never suspected diabetes	√				√							√		√		
Parent knew something was wrong with child (physical or psychological), but only suspected diabetes at a late stage			√	√		√			√		√		√			
Parent knew immediately that child had diabetes							√									
<i>Timing of parent's actions in response to child behaviour or symptoms</i>																
Parent took child to Doctor immediately	√											√				
Parent took child to Doctor after a delay			√	√	√	√	√			√	√		√			
Parent took child to Doctor after child asked to see the Doctor																√
<i>Doctor's diagnosis (or misdiagnosis)</i>																
Doctor (GP) diagnosed immediately			√		√		√			√		√				
Doctor (GP) initially misdiagnosed				√		√					√		√			
Doctor (GP) never diagnosed (i.e. hospital did)	√															
<i>Child's physical condition at diagnosis</i>																
Although had symptoms, did not appear very ill			√	√	√		√					√	√			√
Appeared very ill (although parent might not have noticed this until later – e.g. when looking at photos)	√					√				√	√			√		

APPENDIX 6.12: DIABETES GROUP: Feelings at diagnosis (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Age at diagnosis	4	3	11	2	2	2	9	11	8	11	3	5	11	9	3	12
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Parent feelings when first appreciating diagnosis</i>																
anxiety or distress																
distress / devastated / burst into tears a lot	√	√	√	√					√	√					√	√
shock			√	√		√		√	√	√	√	√	√			
anxiety												√	√		√	√
denying the truth			√	√ (M)		√	√									
bereavement / loss		√	√	√							√			√	√	
being 'practical' / not focusing on emotional side or 'going through the motions'				√ (F)						√						
preoccupied with thoughts about diagnosis and its management (e.g. waking at night)																√
feeling that it was a tough time			√				√	√				√	√	√	√	√
putting on a brave face whilst feeling 'fragile'			√													
evaluation of situation																
bewildered / feeling ignorant	√	√						√	√		√	√	√		√	√
relief (at knowing reason for symptoms)					√											
asking why it happened (genetic? parental error?)			√										√			
worry																
guilty	√		√				√			√						
worry about child and / or other family members	√		√				√	√	√	√		√	√		√	√
worry about impact on self							√									
worry or fear about making mistakes with disease management								√	√						√	
anger, annoyance or frustration																
angry at self for not noticing symptoms or not responding appropriately	√									√						√

APPENDIX 6.12: DIABETES GROUP: Feelings at diagnosis (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Age at diagnosis	4	3	11	2	2	2	9	11	8	11	3	5	11	9	3	12
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
angry at doctors for misdiagnosis, issues with initial management and/or lack of information (some)	√		(√)	√				(√)	(√)							√
blaming others for not noticing symptoms																√
sadness or disappointment																
feeling unsupported by or not trusting health care professionals, thinking nurses didn't know enough										√	√			√		
feeling unsupported by family and friends							√				√		√		√	
positive or neutral feelings																
feeling supported by some health care professionals			√						√		√					√
<i>Post-initial reactions (e.g. after discharge)</i>																
'Get on with it' / learning to cope / do one's best		√			√						√		√			
Found it difficult / upsetting to inject child															√	
Management was like a military operation											√					√
Prayed for a cure																√
Stress in relationship with partner – disagreements over management or feeling partner not sharing load								√			√					
Felt greater sense of responsibility, wanting to 'let go' with adolescent, but finding this difficult			√													
Dawning realisation of significance												√		√		
Try to be positive, take a day at a time													√			
Easy to adapt					√											
Became more assertive with doctors	√															
'Flying by the seat of our pants'											√					
Compared own child to another much worse off – turning point that made adjustment easier						√					√					

APPENDIX 6.12: DIABETES GROUP: Feelings at diagnosis (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Age at diagnosis	4	3	11	2	2	2	9	11	8	11	3	5	11	9	3	12
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
Parent emotional expression during interview (when describing initial experiences)																
upset / crying				√ (M)					√	√	√		√ (M)			√
Parent reflection on how this is represented by them in their minds																
describes experience as 'vivid' in mind (very detailed description)	√			√ (M)								√				

APPENDIX 6.13: ASTHMA GROUP: Later and present feelings (shaded cells in box at top replicated from Appendix 6.11)

*no further entries for A_13, as this child has not yet had the diagnosis of asthma confirmed

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Age at diagnosis	2	1	2	<1	1½	2	1	2	1	8	2	-	2	2	1½	2
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Parent observations prior to diagnosis</i>																
Night-time coughs / coughing				√	√	√						√		√		
Night-time wheeze / wheeze	√	√	√				√		√	√	√	√	√	√	√	√
Vomiting feeds				√									√			
Breathless		√			√		√	√	√	√	√			√	√	√
<i>Parent description of kind of onset</i>																
Initial severity of asthma = mild	√		√	√		√			√	√		√	√			
Initial severity of asthma = moderate or severe		√			√		√	√			√			√	√	√
<i>Turning points in illness severity (if any)</i>																
Worse, then better	√	0	√	1	0	√	0	0	√	1	0	1	0	1	2	0
Better, then worse															√	
Only worse				√								√				
Only better									√					√		
No change		√			√		√	√			√		√*			√
<i>Later or current feelings</i>																
anxiety																
significant anxiety at times		√		√			√	√ (M)				√		√		
mild anxiety at times			√					√ (F)							√	
panic or fear (during severe attacks)		√				√	√					√			√	
goes on 'autopilot' / feels temporarily numb during acute admissions		√														
during acute admissions, try to only focus on the immediate, to avoid crying		√														

APPENDIX 6.13: ASTHMA GROUP: Later and present feelings (continued)

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Age at diagnosis	2	1	2	<1	1½	2	1	2	1	8	2	2	-	2	1½	2
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
anxiety (continued)																
preoccupied with symptoms – thinking about it and listening / observing occupies much time							✓					✓				✓
extra vigilant / acute / ‘senses prickled’			✓					✓				✓		✓	✓	✓
feels emotionally drained					✓											
feeling that it is a tough time / hard to cope					✓	✓						✓				
finding it hard to respond to child’s negative feelings and bitterness					✓											
feeling that child could have died or could die			✓									✓		✓		
stress in relationship with partner – relating to different levels of anxiety							✓	✓								
re-experiences original fear and traumatic feelings during acute admissions															✓	
<i>Later or current feelings (continued)</i>																
worry																
worry about not being able to recognise attack			✓													
worry due to own lack of understanding during acute admissions		✓														
thinks GP is fed up with them as parents, but feels better after visit																✓
worry about future attacks and / or those occurring when away from home							✓				✓					✓
worry about drug side effects and getting the balance right (for controlling symptoms)									✓							
worry about potential need to be hospitalised						✓										✓
worry about practical if hospitalised (e.g. child care)						✓										
worry about making wrong judgement about making child go to school when she’s unwell				✓												

APPENDIX 6.13: ASTHMA GROUP: Later and present feelings (continued)

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Age at diagnosis	2	1	2	<1	1½	2	1	2	1	8	2	2	-	2	1½	2
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
worry (continued)																
worry that new school will be able to manage attack											√					
worry that child isn't reliable in tx management															√	
worry about child being held back or other long term effects		√					√									
worry about whether diagnosis was wrong, and illness is something different				√												
worries about juggling home and work				√												
guilt																
feels guilty that made wrong decision prior to attack			√													
feels guilty about being too complacent at times with managing illness				√											√	
feels guilty that sometimes doesn't give best at work				√												
sadness, disappointment or upset																
disappointed child has not grown out of asthma, when had expected him to do so								√ (M)								
feels very alone		√														
feels it's difficult when child can't communicate his feelings		√														
feels sorry for child and upset at their symptoms							√									
frustration, annoyance or anger																
frustrating that not able to fully help child understand why he has to have this treatment					√										√	
feels annoyed at others' ignorance of how serious asthma can be (e.g. if exposed to animals)	√															

APPENDIX 6.13: ASTHMA GROUP: Later and present feelings (continued)

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Age at diagnosis	2	1	2	<1	1½	2	1	2	1	8	2	2	-	2	1½	2
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
frustration, annoyance or anger (continued)																
thought not enough information given by staff during hospital admission		✓														
feels annoyed at doctor									✓						✓	
physical effects																
tired due to disturbed nights				✓		✓										✓
Positive or neutral feelings																
feels happy knowing the trigger for attack												✓				
feels they're getting better at 'letting go'								✓								
Adjusting life to demands of illness (part of life now) / more accepting		✓		✓				✓								✓
not too bad because child still able to do things	✓			✓												
feels disease is easier to manage with experience / feel more in control				✓				✓							✓	
feels a closer bond now with child / protective		✓					✓									
feels confident child will grow out of illness									✓							
confident in being assertive with doctors															✓	
feels better now asthma is improving and child has better understanding															✓	
feels more calm than previously							✓									
hopes child will grow out of illness											✓					
feels lucky (that child survived)			✓													
other feelings about illness impact																
never thought child would get severe asthma												✓				
feels upset that child can't do certain things		✓						✓								

APPENDIX 6.13: ASTHMA GROUP: Later and present feelings (continued)

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Age at diagnosis	2	1	2	<1	1½	2	1	2	1	8	2	2	-	2	1½	2
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Parent actions</i>																
goes to the GP every time child has a cold																✓
always attend clinic appointments and follow medical advice			✓													
do some activity to attempt to improve health or reduce risk									✓							✓
<i>Parent feelings now (if recently turning point)</i>																
relief (starting to see an improvement – no bad attacks recently)						✓										
feeling happier and more relaxed due to recent improvement			✓			✓										
hopeful child would outgrow it						✓										
Parent emotional expression during interview (when describing limitations on child's life)																
upset / crying		✓						✓								

APPENDIX 6.14: DIABETES GROUP: Later and present feelings

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Age at diagnosis	4	3	11	2	2	2	9	11	8	11	3	5	11	9	3	12
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Parent observations and thoughts prior to diagnosis</i>																
Parent noticed behavioural changes but didn't ever think anything was wrong with child physically										√						√
Parent knew something was wrong with child physically, but not what – never suspected diabetes	√				√							√		√		
Parent knew something was wrong with child (physical or psychological), but only suspected diabetes at a late stage			√	√		√			√		√		√			
Parent knew immediately that child had diabetes							√									
<i>Timing of parent's actions in response to child behaviour or symptoms</i>																
Parent took child to Doctor immediately	√											√				
Parent took child to Doctor after a delay			√	√	√	√	√			√	√		√			
Parent took child to Doctor after child asked to see the Doctor																√
<i>Doctor's diagnosis (or misdiagnosis)</i>																
Doctor (GP) diagnosed immediately			√		√		√			√		√				
Doctor (GP) initially misdiagnosed				√		√					√		√			
Doctor (GP) never diagnosed (i.e. hospital did)	√															
<i>Child's physical condition at diagnosis</i>																
Although had symptoms, did not appear very ill			√	√	√		√					√	√			√
Appeared very ill (although parent might not have noticed this until later – e.g. when looking at photos)	√					√				√	√			√		

APPENDIX 6.14: DIABETES GROUP: Later and present feelings (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Age at diagnosis	4	3	11	2	2	2	9	11	8	11	3	5	11	9	3	12
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Later or current feelings</i>																
general feelings or evaluations about illness impact																
positive																
feels disease is easier to manage with more knowledge and experience / less regimented / feel more in control	√			√ (F)	√				√		√			√		
adjusting life to demands of illness (part of life now) / more accepting / 'get on with it'	√		√		√	√		√		√		√			√	√
take a day at a time, do what's required, don't worry or think about it too much	√					√										
feels more relaxed than previously				√							√					
starting to learn to cope with it													√			
hopes for cure or child will benefit from future research to make treatment easier			√	√									√			
feeling that child and parents have done well					√					√						
more open now with others about child's illness																√
learning to trust child / able to 'let go'			√													√
feels reassured that child has accepted it																√
feels reassured that there is someone available to help if parents make a mistake with treatment			√		√											
feel lucky to be a couple and have each other's support														√		
feel reassured by positive feedback from HbA1c tests					√											

APPENDIX 6.14: DIABETES GROUP: Later and present feelings (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Age at diagnosis	4	3	11	2	2	2	9	11	8	11	3	5	11	9	3	12
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
negative																
get it wrong sometimes – perhaps get too blasé over time					√			√								
diabetes takes over your life if you're a conscientious parent (treatment continually preoccupies thoughts and actions)												√	√		√	
parent had thought it was going to be easier												√	√			
feeling of having too much responsibility / always 'on call' / like having a baby again												√ (F)	√	√		
don't yet feel able to 'let go'									√	√		√				
realisation that diabetes is for life, and you can never get away from it			√				√						√			
feels as bad as when diagnosed; it hasn't gotten any better							√									
diabetes comes between child and parent in their relationship							√							√		
it is discouraging when blood sugars are stubbornly high in evenings					√											
feels don't have enough information from health professionals (about diet)					√ (F)								√			

APPENDIX 6.14: DIABETES GROUP: Later and present feelings (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Age at diagnosis	4	3	11	2	2	2	9	11	8	11	3	5	11	9	3	12
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
neutral / mixed feelings																
accepting nothing could have been or could be done to change the situation	√															
would like to change places with child if they could			√				√						√			
still learning all the time / doing one's best within limits of knowledge			√	√	√			√				√				√
feels more 'grown up' as a person												√ (F)				
sees disease management in context of overall challenge of adolescence								√ (F)	√							
at times when child's control is better, child and parents are less anxious (and the reverse)													√	√	√	
sometimes sees self as lucky when appreciating worse problems of other children – reminds self and / or child of this when feeling sad	√		√			√			√							√
not too bad because child still able to do things																√
good days and bad days, depending on what else is going on in the family			√												√	
some luck is involved in 'getting it right'					√											

APPENDIX 6.14: DIABETES GROUP: Later and present feelings (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Age at diagnosis	4	3	11	2	2	2	9	11	8	11	3	5	11	9	3	12
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
anxiety																
significant anxiety at times			√		√(M)								√	√	√	
mild anxiety at times			√	√(F)	√				√	√	√			√	√	
consumed with worry when control is bad – on edge, can't plan anything															√	
lacks confidence in the ability of others to treat child properly during emergencies (due to poor knowledge)		√	√						√			√				
anxious about not getting the blood sugars right, despite parents' best efforts		√	√		√(F)		√						√	√		
upset that can't get partner to understand aspect of treatment this parent thinks is detrimental					√(F)											
feels emotionally drained															√	
stress in relationship with partner – e.g. relating to different priorities (physical vs psychological)					√			√								
<i>Later or current feelings (continued)</i>																
worry																
concerned about dealing with child's bad moods				√(M)										√		
concerned that don't know others who could do the injection				√												
whilst at work, worrying that child was OK at nursery				√(M)												
concerned that maybe parents monitor blood glucose too closely (giving more high readings)												√				

APPENDIX 6.14: DIABETES GROUP: Later and present feelings (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Age at diagnosis	4	3	11	2	2	2	9	11	8	11	3	5	11	9	3	12
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
worry about future attacks and / or those occurring when away from home or when unobserved (e.g. at night)					√									√		
worry about getting the balance right (between strict control and flexibility to be more normal)								√						√		
worry about school not being able to manage the diabetes									√			√				
sometimes expects something to go wrong										√						
worry about being 'too pushy' with child										√						
don't like to keep bothering relatives to ask for help, so cope alone							√									
worry that sibling isn't getting enough attention														√		
worry that child might not be reliable in treatment management									√		√		√	√		√
worry about child being held back or other long term effects (e.g. not becoming independent)													√			
guilt																
feels guilt of carrying diabetes genes				√												
feels guilty about being too complacent at times with managing illness									√							
feel guilty about a termination some years previously, which was of not feeling able to cope														√		

APPENDIX 6.14: DIABETES GROUP: Later and present feelings (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Age at diagnosis	4	3	11	2	2	2	9	11	8	11	3	5	11	9	3	12
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
sadness, disappointment or upset																
upsetting at not having good control		√											√			
'heart-wrenching' to see child having to inject themselves													√			
feels sad that can't get child to accept diabetes and its effects on life							√								√	
feels that child doesn't take more responsibility							√								√	
hates having to nag child to remember injection							√						√			
feel sad at not having any free time as couple or individuals												√				
sometimes feels sad that child will miss out in some aspects of life, or find them more difficult						√										
sadness that wife had a termination because it would be too much with the diabetic child too														√		
deep down resentment sometimes / cries or moans										√						√
feels alone or unsupported by family at times							√		√	√	√					
feels other people blame parent for not getting treatment right, when they do their best									√							
frustration, annoyance or anger																
doctors don't have realistic understanding of how much diabetes impacts life or how hard it is – they don't 'live it'									√			√				
frustrating that not able to fully help child understand need to avoid long term risks							√	√								
feels annoyed at lay peoples' / family members' ignorance about diabetes – sometimes inappropriate comments or behaviour	√					√			√			√				

APPENDIX 6.14: DIABETES GROUP: Later and present feelings (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Age at diagnosis	4	3	11	2	2	2	9	11	8	11	3	5	11	9	3	12
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
frustration, annoyance or anger (continued)																
frustrated when health professionals get it wrong (due to ignorance)	√											√				
sometimes having to make adjustments because of the disease is annoying						√										
frustrated that can't get to grips with an aspect of treatment					√ (F)											
Parent emotional expression during interview (when describing limitations on child's life)																
upset / crying										√						

APPENDIX 6.15: ASTHMA GROUP: Concerns and hopes for the future

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Age at diagnosis	2	1	2	<1	1½	2	1	2	1	8	2	2	-	2	1½	2
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Parent observations prior to diagnosis</i>																
Night-time coughs / coughing				√	√	√						√		√		
Night-time wheeze / wheeze	√	√	√				√		√	√	√	√	√	√	√	√
Vomiting feeds				√									√			
Breathless		√			√		√	√	√	√	√			√	√	√
<i>Parent description of kind of onset</i>																
Initial severity of asthma = mild	√		√	√		√			√	√		√	√			
Initial severity of asthma = moderate or severe		√			√		√	√			√			√	√	√
<i>Turning points in illness severity (if any)</i>	2	0	2	1	0	2	0	0	2	1	0	1	0	1	2	0
Worse, then better	√		√			√			√							
Better, then worse															√	
Only worse				√								√				
Only better										√				√		
No change		√			√		√	√			√		√*			√
<i>Hopes for the future</i>																
Child continues to cope well (helps parent cope)						√										
Hopes child will be confident in life and be able to do normal things, whilst managing risk		√						√								
Parent will not need to have so much responsibility with better asthma control		√				√										
Longer the gaps between acute episodes gives parent increasing confidence in improvement		√										√				
Hopes / prays child will grow out of asthma		√								√						√
Doesn't think child will grow out of it, but hope it improves									√							
Hopes new school will safely and knowledgeably care for child	√															

APPENDIX 6.15: ASTHMA GROUP: Concerns and hopes for the future (continued)

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Age at diagnosis	2	1	2	<1	1 ½	2	1	2	1	8	2	2	-	2	1 ½	2
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>concerns about the future</i>																
short-term																
worry about worsening asthma when weaned off drugs						√										
worried about getting an infection in hospital													√			
worried that pre-school / school won't cope with the asthma safely and knowledgeably	√											√	√			
worry about child falling behind at school							√									
long term																
concerned about long-term side effects of drugs					√		√		√							
concerned about long-term effects of having many chest infections							√									
finding the right balance with drugs (minimise side effects whilst still controlling asthma)									√							
asthma might not disappear – have it for life, have drugs for life		√			√											√
worry that asthma will get worse in future				√						√				√		
worry that the asthma will hinder them for the rest of their lives / not have normal experiences		√	√													
concerned that child might not cope without parent's help (e.g. at secondary school, at sleepovers, leaving home)			√					√ (M)			√	√				

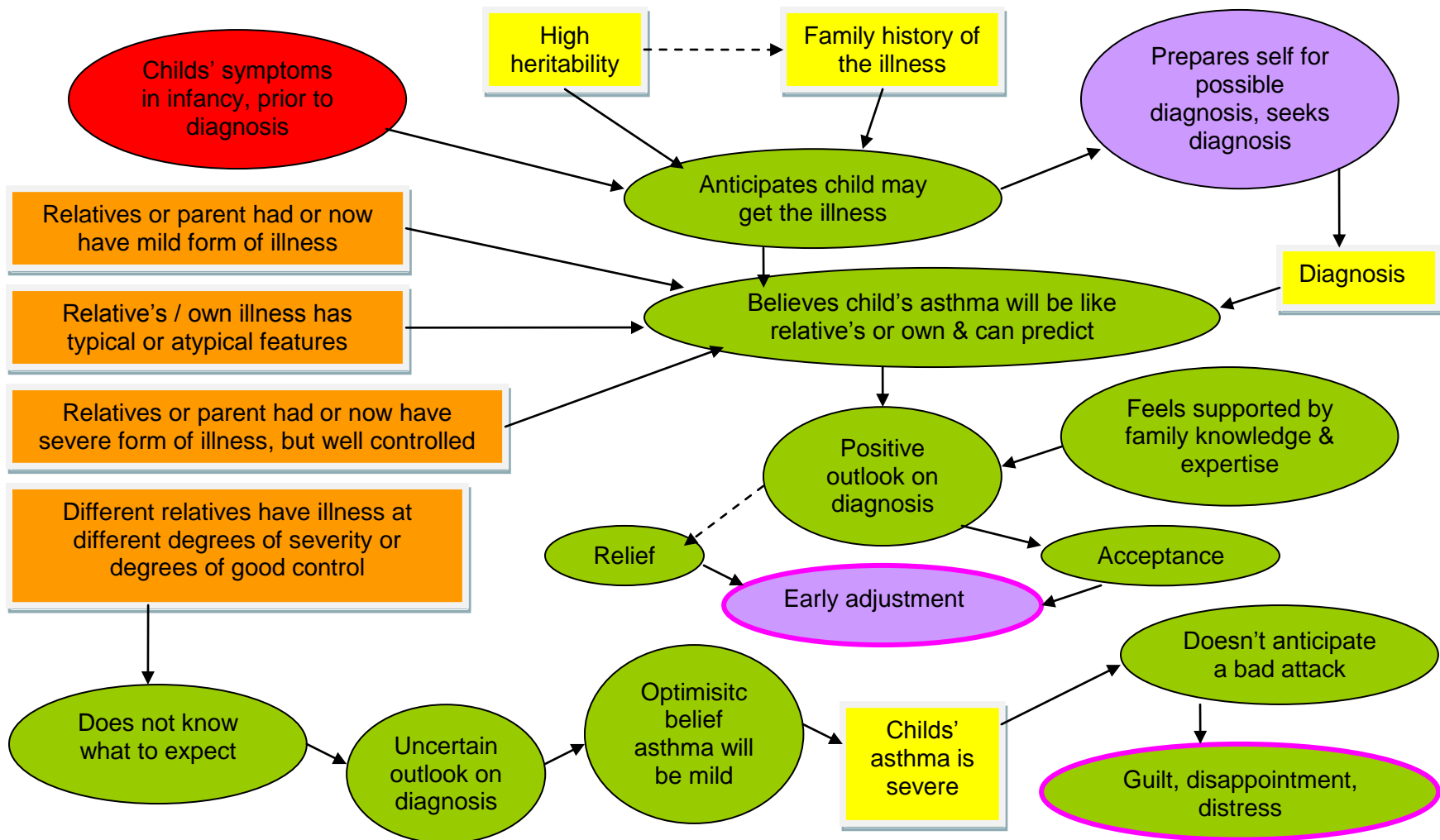
APPENDIX 6.16: DIABETES GROUP: Concerns and hopes for the future

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Age at diagnosis	4	3	11	2	2	2	9	11	8	11	3	5	11	9	3	12
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Hopes for the future</i>																
Hopes child will become more responsible with age and accept diabetes more							<									
Hopes child will be confident in life and be able to do normal things, whilst managing risk				√				√							√	√
Hopes child won't get serious complications / stays in good health				√				√								
Hopes / prays for a cure				√		√										
Doesn't think there will be a cure, but hopes for improvements in treatment																
<i>concerns about the future</i>																
short-term																
not worried / don't think about it						√										
worried about getting treatment right													√			
worried that school won't cope with the diabetes safely and knowledgeably																
worry about child falling behind at school																
long term																
concerned about long-term complications of the disease (due to poor blood glucose control)				√			√	√ (M)				√ (M)	√			√
sometimes few seconds' worries about complications						√										
worry about child not taking responsibility when reaches teenage / young adult years				√			√	√ (F)								
concerned that child might not cope / get treatment right without parent's help (e.g. at secondary school, at sleepovers, leaving home)				√			√			√		√	√			√

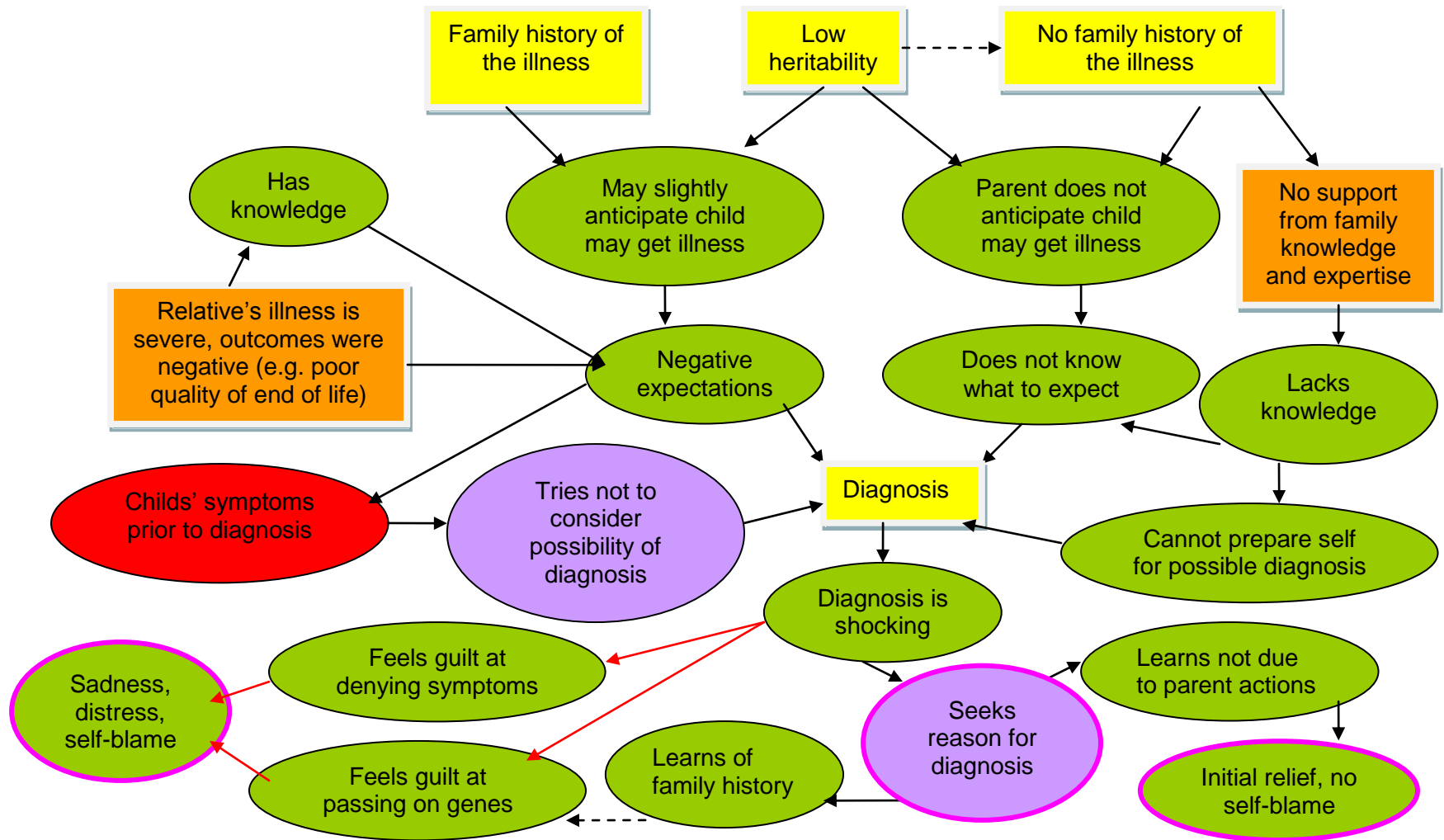
APPENDIX 6.16: DIABETES GROUP: Concerns and hopes for the future (continued)

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Age at diagnosis	4	3	11	2	2	2	9	11	8	11	3	5	11	9	3	12
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
worry that sibling will get diabetes				√									√			
worry that child might not experience normal things of life that other people do									√			(F) √				
worry that diabetes will hinder their lives / not have normal experiences							√					(F) √				
worry that will continue to experience constant threat of unexplained hypos												(F) √				

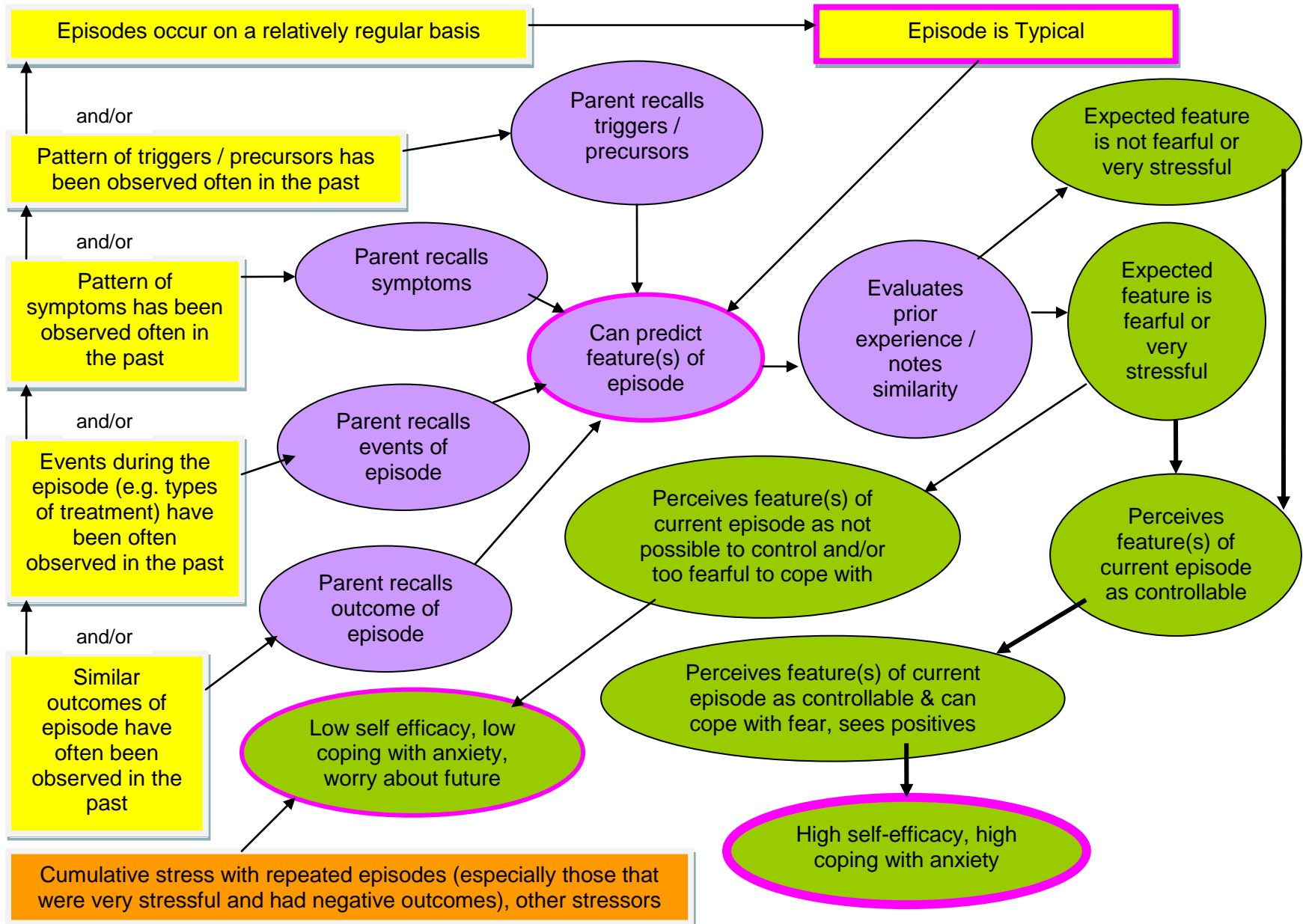
Appendix 6.17: Schematic Diagram 16: Family history of illness with high heritability (Asthma): impact on parent adjustment



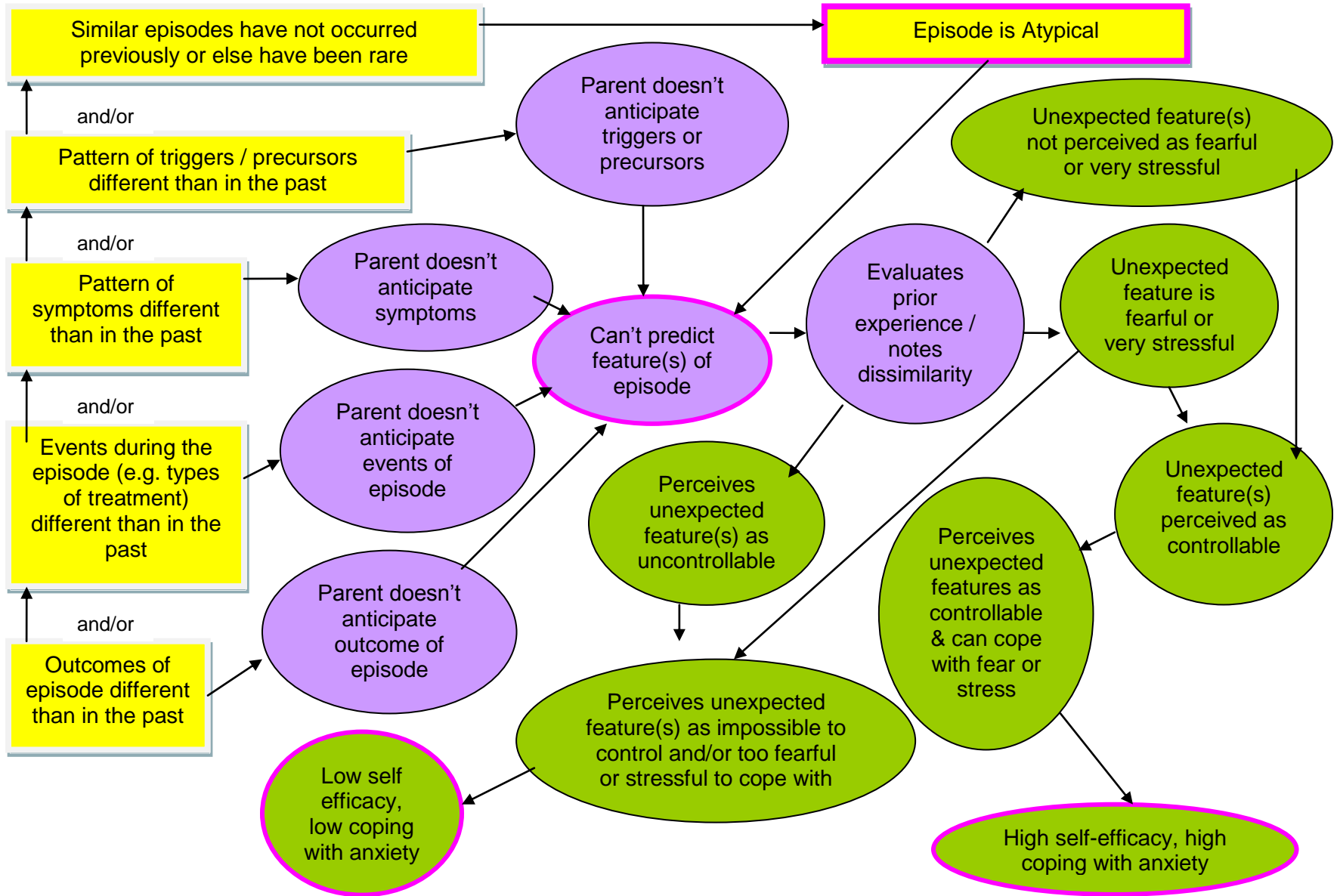
Appendix 6.18: Schematic Diagram 17: Family history of illness with low heritability (Type 1 Diabetes): impact on parent adjustment



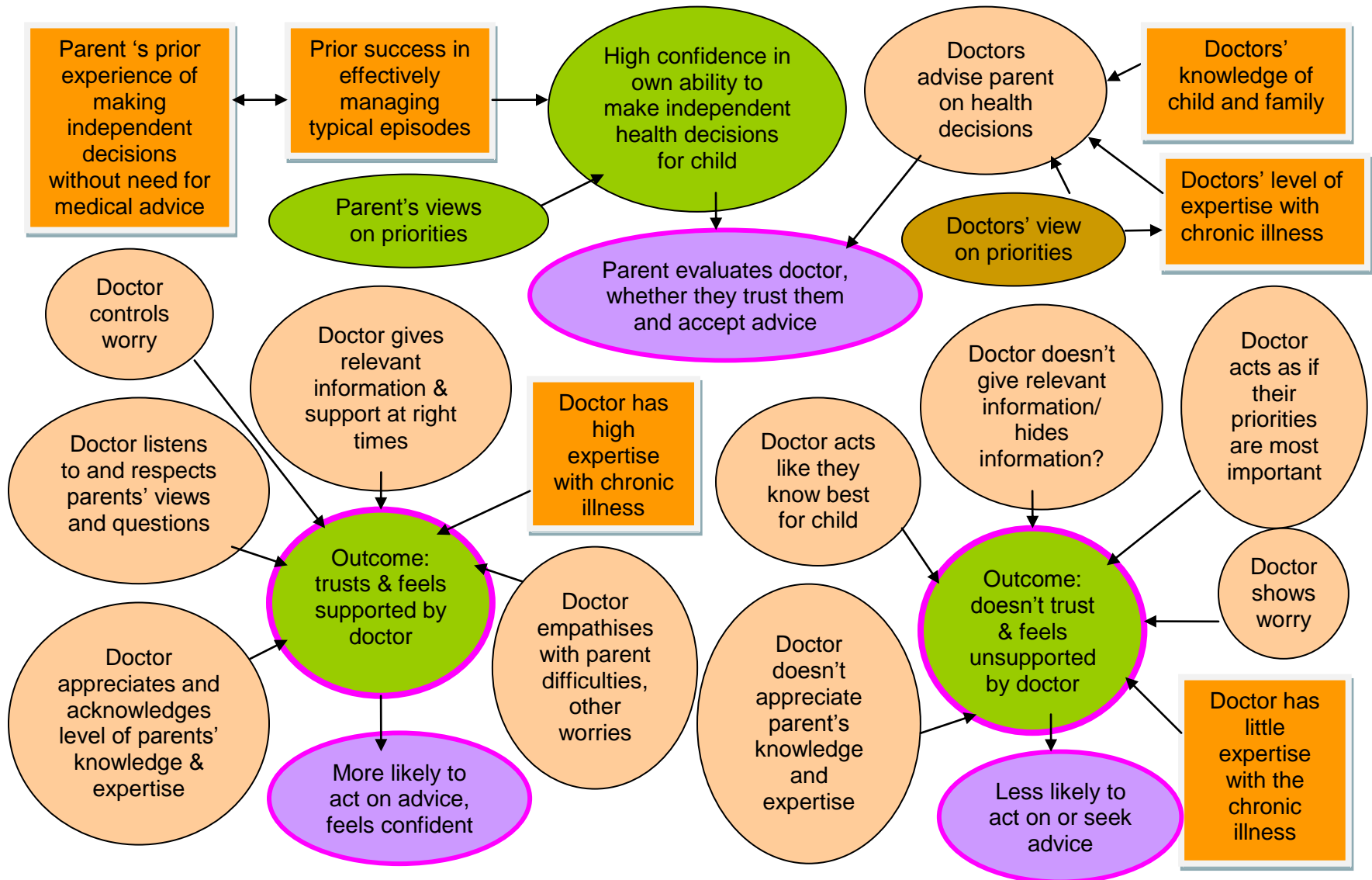
Appendix 6.19: Schematic Diagram 18: Parent perceptions and responses during typical episodes – both illness groups



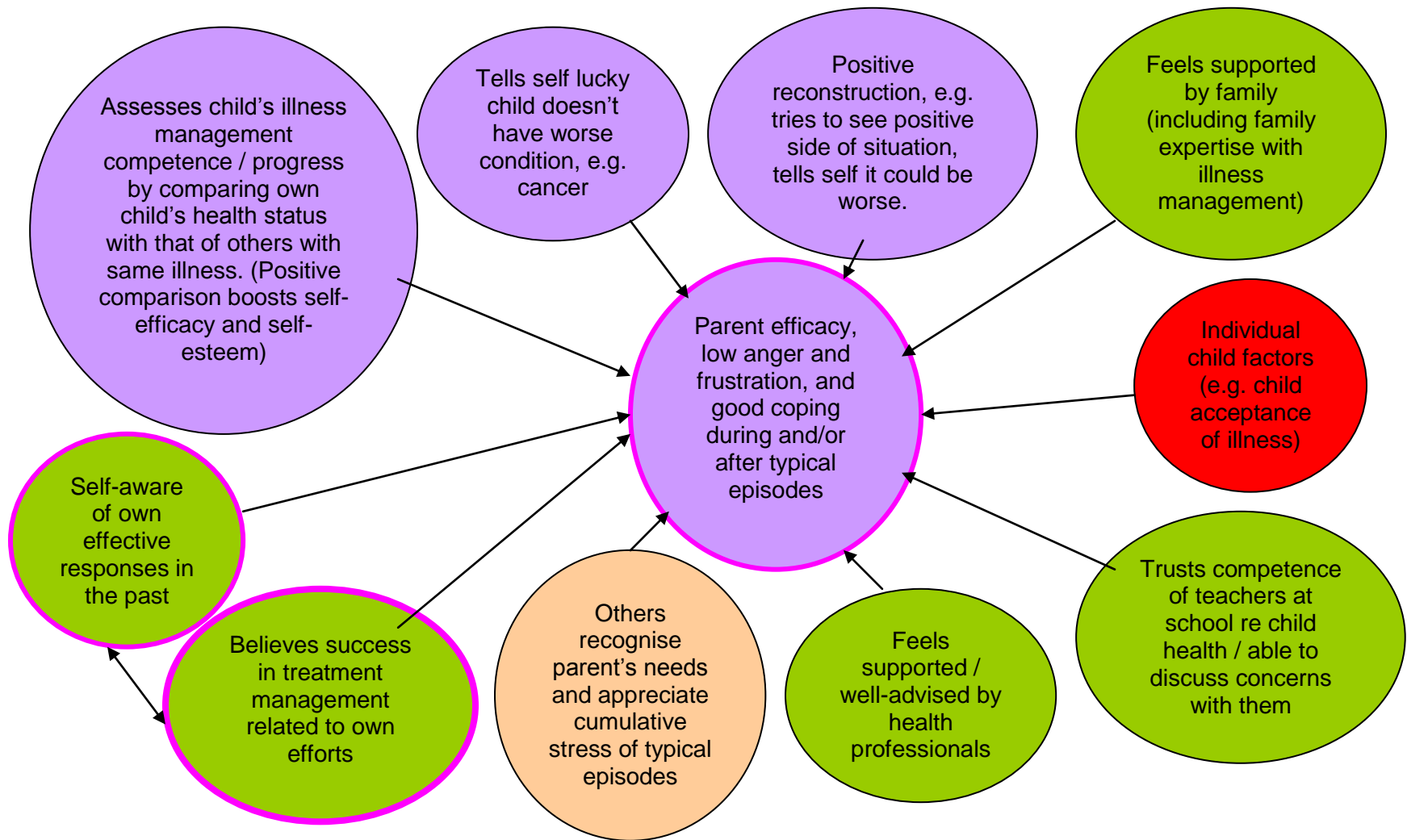
Appendix 6.20: Schematic Diagram 19: Parent perceptions and responses during atypical episodes – both illness groups



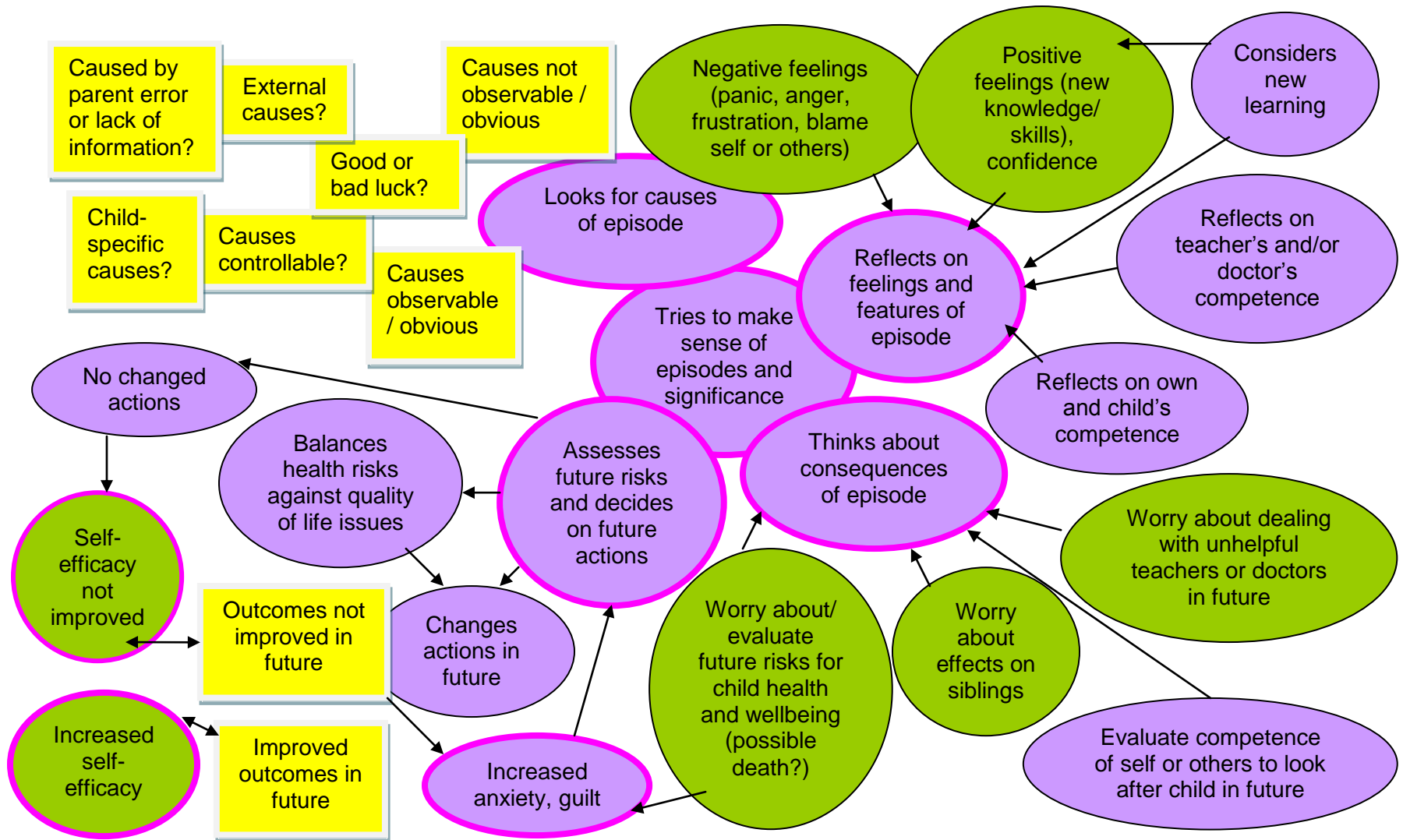
Appendix 6.21: Schematic Diagram 20: Parent evaluations of interactions with doctors during typical episodes – both illness groups



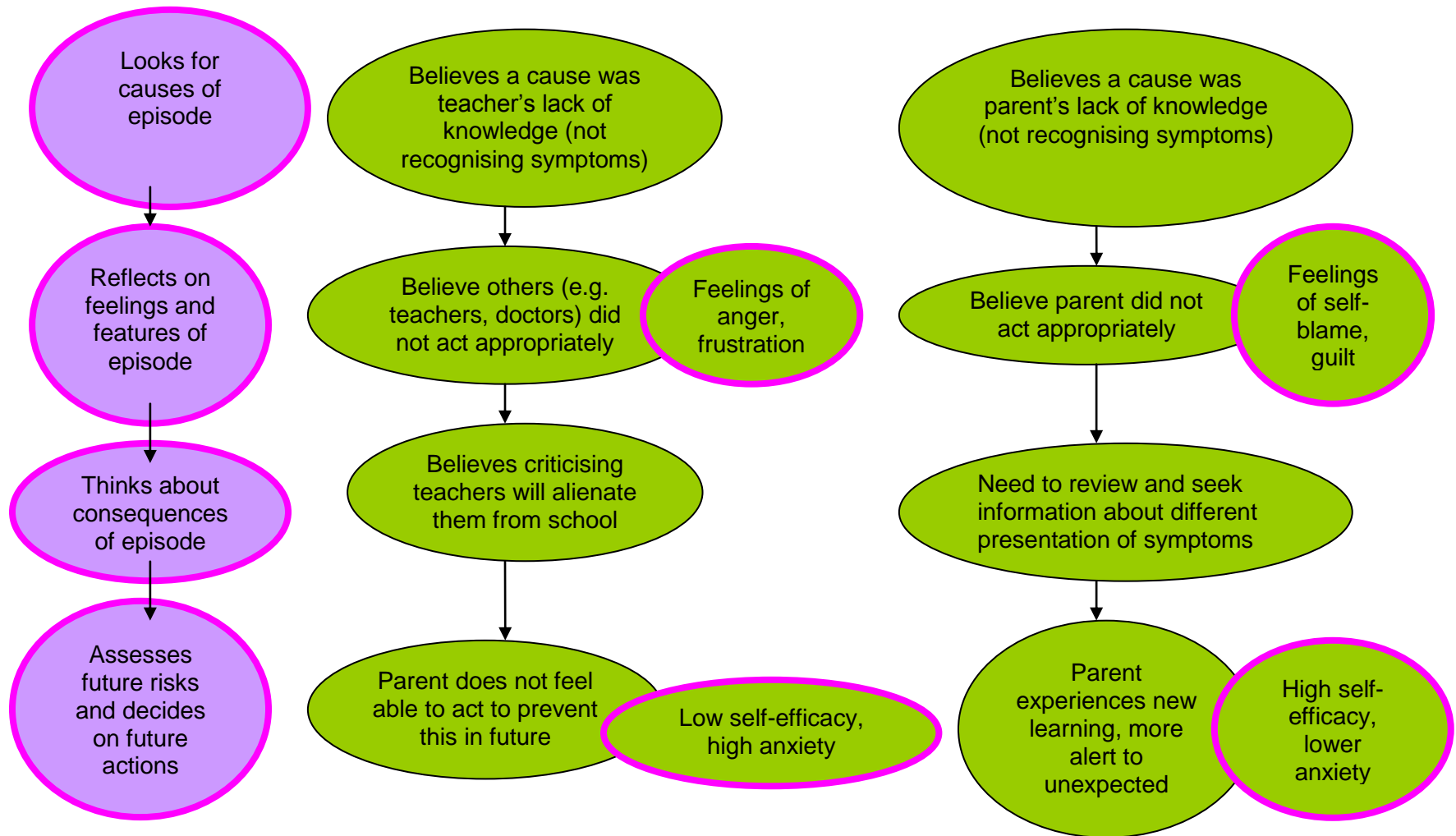
Appendix 6.22: Schematic Diagram 21: Factors contributing to parents' efficacy, low frustration and good coping during and after typical episodes – both illness groups



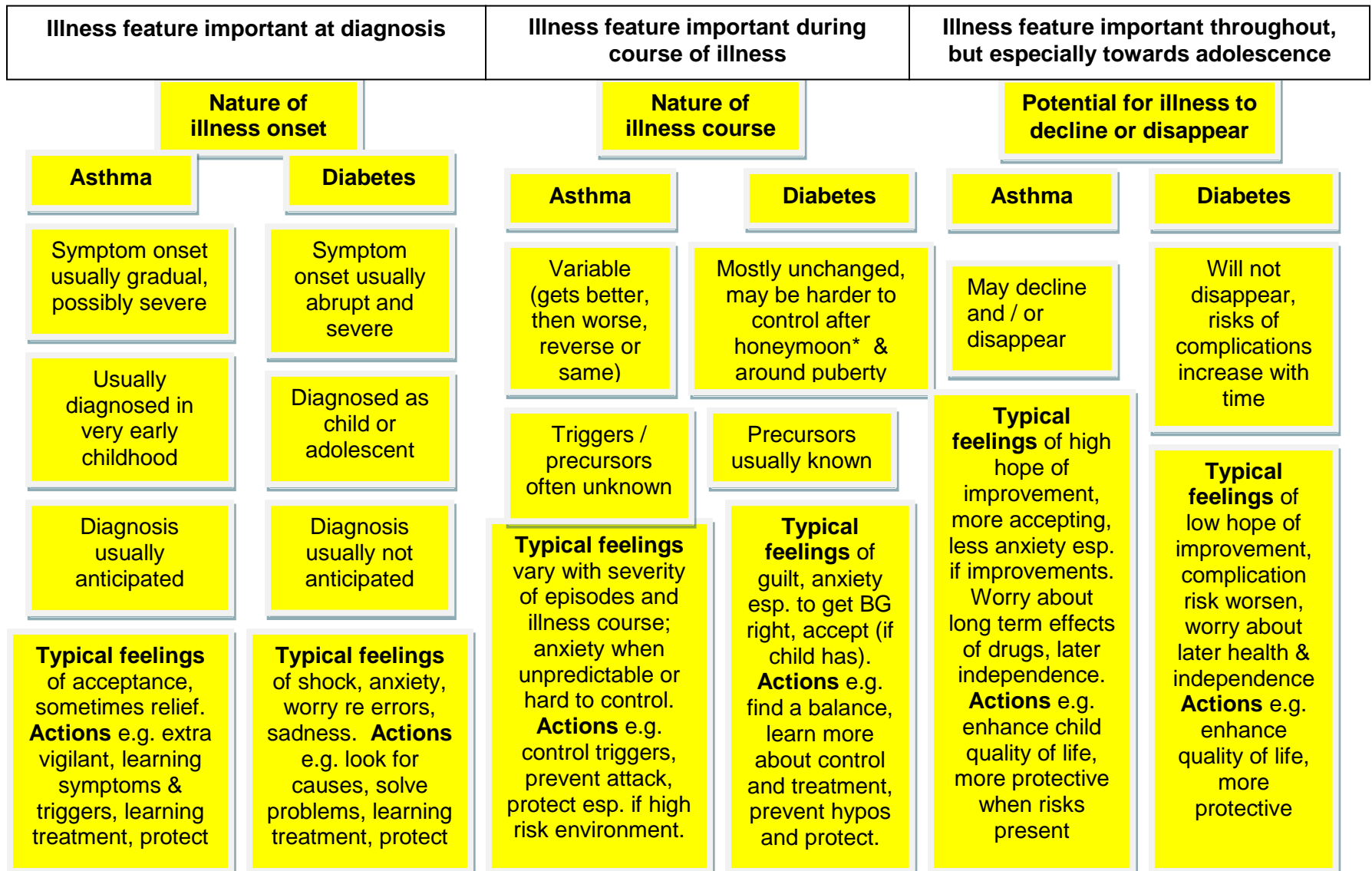
Appendix 6.23: Schematic Diagram 22: Process and outcomes for parents following reflection on typical and atypical episodes (particularly those not well managed) – both illness groups



Appendix 6.24: Schematic Diagram 23: Significance of parents' evaluations in atypical situations: contrasting examples of external and internal attribution



Appendix 6.25: Schematic Diagram 24: Features of illnesses impacting on adjustment over time: comparison of the two illness groups



* A 'honeymoon period' is often described in the weeks and months post-diagnosis, referring to a period when blood glucose control seems good and little insulin is needed, but this doesn't usually last beyond a few months, perhaps a year. Control can therefore be more difficult when emerging from this honeymoon period; this is one reason why focus on control /being vigilant is so high at this time.

APPENDIX 7.1: IMPACT ON PERSONAL LIFE – ASTHMA GROUP (NB Separately considering family life)

Participants	Aspect of personal life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
A_2, A_6, A_7	Sleep	Tiredness due to child night waking Woke up when child regularly unwell and needing treatment	Tiredness had big impact when child unwell	Still tired, but also due to demands of other children, not just asthma	Night waking impacts on life, but not on day-to-day basis (A_6) Can affect coping and health (A_7)
A_10	Sleep	Tiredness due to night waking Child unwell 4-5 times / year when very wakeful	Very tired	Not so bad now	Not discussed
A_12	Sleep	Tiredness, especially during hospitalisation Became exhausted during child hospitalisation	Affected working life	Not hospitalised, but still not 'recovered' from tiredness	Reflects that can't avoid problem, as must be sole carer in hospital, not possible to share load with husband (not capable, child wouldn't like it), but can reduce workload to recover. Appreciates Dr's recognition and actions (making her go home).
A_16	Sleep	Tiredness due to child's regular waking	Due to asthma, but also bad dreams relating to medication, hospitalisation	Child wakes nightly, but not necessarily due to asthma	Instituted star chart to encourage child to sleep through night.
A_4	Sleep	Tiredness due to waking at night and working during day	Carried on working as had good childminder nearby	Continues to feel tired due to lack of sleep.	Tries to get on with life.

Participants	Aspect of personal life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
A_6	Vigilance and monitoring	Being extra vigilant, monitoring, listening		Always watching, listening for symptoms	Impacts on life, as always aware
A_16	Vigilance and monitoring	Being extra vigilant, monitoring, listening. Part of normal life.	Necessarily action.	Yes	Always doing this, so don't know other way; perceive they worry more than other parents.
A_11, A_9	Vigilance and monitoring	More alert to problems when ill	Tendency to worry more	Tendency to panic more when poorly.	Not too much effect when well
A_16, A_10, A_2	Time and effort of treatment	Demands of treatment – effort. Carries puffer in bag, ensures available medication	Necessary action, need to be very organised	Yes	No change
A_5	Time and effort of treatment	Treatment (eczema) was time consuming Regular treatments become routine. Time consuming and effort in hospital.	Necessary action. Needed to involve family to help with childcare.	Time consuming getting prescriptions and taking time out for hospitalisations.	Annoyed that getting prescriptions is a laborious process.
Frost	Time and effort of treatment	Difficultly fitting in 6 nebuliser treatments per day.	It was 'a pain' to fit in.	No longer nebulising	Quite good to have stopped this.
A_6	Working life	Called away by school when child unwell, or stayed at home with sick child. Worries about who to look after child when not so well and need to work.	Limited ability to work regularly and consistently, stressful trying to juggle things.	Sometimes	Not mentioned

Participants	Aspect of personal life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
A_13	Working life	Taking time off work to be in hospital (F)	Has to make up the time at work (F)	Same	Same
A_12	Working life	Repeated hospitalisations were time consuming, not available to work	Fell behind in self-employed work	Hospitalisation has been time consuming	Difficult to catch up, so reducing own workload, recognised needed to reduce pressure
A_4	Working life	Sometimes had to take time off work if unwell, finds it difficult to juggle work and home commitments	Worry about whether to or not send child to school.	Same	Still concerns about whether to take day off or not when unwell, and feels guilty if pushes child to school, feels doesn't give best to job but they're supportive. Easier as work across road from school.
A_5	Working life	Had time off if child hospitalised	Worked few hours (6 hrs/wk). Not too bad, as worked on hospital site	Works more hours, less likely to take time off work as working on site, and can be called if needed. Takes time off work if child on nebuliser.	Not too bad, as he is older and able to be more by himself, and works close to home so could come home quickly if needed.
A_15	Working life	Had time off frequently due to frequent child hospitalisations	Stressful due to not understanding boss and lots of back and forth. Used up annual leave, so no breaks /hols.	No	Not problem now

Participants	Aspect of personal life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
A_5	Potential career	Would have liked to have studied midwifery.	Disappointed, but felt impossible due to frequent illness episodes.	Feels now too long out of education to do it.	Bothers her that she never did it.
A_2	Potential working life	Did not return to work full time. No suitable childminder, so worked opposite shifts.	Not successful arrangement – partner not supportive when child ill.	Now no longer working and with different partner.	Believes this contributed to relationship breakdown with partner (felt unsupported).
A_13	Potential working life	Did not return to work part-time as had anticipated.	Not too disappointed	Same	Same
A_11	Potential working life			High number of children rather than having child with asthma meant not working.	Hopes to get a job when children are older.
A_6	Socialising / going out with partner or friends	Rarely socialised due to being single working parent with 4 children	Laughed at question – ‘no social life’	Same	Apparently accepting
A_13	Socialising / going out with partner or friends	Don’t go out in evenings	Won’t leave with babysitter, except Grandmother	Same	Same
A_16	Socialising / going out with partner or friends	Life rotates around the child	Won’t leave with babysitter	No change	Apparently accepting, don’t mind

Participants	Aspect of personal life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
A_15	Socialising / going out with friends	Couldn't plan as child's health unpredictable	Felt had no personal life	As child older, less impact, can leave with Grandma	'Getting drunk with friends solves many a problem'
A_9, A_7	Socialising / going out with friends husband	When child unwell, don't go out	Not discussed	Same	Same
A_4, A_7	Socialising / going out with partner or friends	Rarely went out	Only trusted relatives able to look after	Still doesn't go out much	Would leave with trusted relatives.
A_3, A_11	Socialising / going out with friends	Doesn't go out anyway socially.	OK	No change.	Didn't affect social life as didn't go out before anyway.
A_2, A_3	Socialising / having a break			No longer visits anywhere smoky.	Feels not going smoky places restricts places to go. (A_2) Stops child's older sister from smoking in the house
A_2	Socialising / having a break			Does go out sometimes. Sometimes ex-partner or babysitter looks after child.	Feels when ex-partner takes over is the only time parent has proper break, feels rejuvenated as not worrying. Doesn't enjoy going out, as worrying all evening about whether child is alright, phoning home etc.
A_2	Visiting relatives			Only short visits possible with mother as has dog (needs child with her)	Not discussed

Participants	Aspect of personal life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
A_12	Extra housework	Changes covers, protections, boiled toys, frozen toys	No effect of this effort on child's asthma	No	N/A
A_16, A_7	Extra housework	Hoover bed, wash duvet in hot water weekly, boil toys, dusting	Has improved asthma	Still does this	Doesn't affect her as likes cleaning.
A_3	Extra housework	More sweeping to reduce dust	Difficult to do this on farm	Same	Same
A_5, A_7	Changes to living environment and financial outlay	Moved house, removed all carpets, anti-allergy bed, etc.	Helped asthma		
A_2, A_7	Change of parent's habits			Smoking only in garden	Not discussed (A_2) Would like to quit (A_7)
A_12	Feeling weight of responsibility			Feels things fall to her as the mother	Copes by talking about it
A_5	Feeling weight of responsibility			Ex-husband brings child back home during night if unwell.	Ex-husband now has nebuliser at his home.
A_2	Feeling weight of responsibility			Ensures everyone has inhalers, multiple locations.	Feels has to make sure everyone else is prepared, not just self.
A_4	Feeling weight of responsibility			Often left to make decisions, as single parent and hcp.	Feeling unable to hand on responsibilities, worry about bothering doctors
A_8	When socialising with other mothers, being known as parent of child with asthma	People tell parent horror stories or risks about asthma that are frightening	Angry at these people	Constantly bombarded by such comments.	Exacerbates worry, they don't understand impact.

Participants	Aspect of personal life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
A_5	Financial impact	Expenses of treatments plus having 3 other children, house A_12s slumped and needed bigger house	Worried about finances, but was told about and helped to apply for disability benefits and this helped.		
A_7	Financial impact	Husband has time off work when child ill, to look after other 3, extra costs at hospital	Disrupts life		
A_4, A_2, A_7	Being restricted on going out of house	When very ill, not able to go grocery shopping or anywhere else.	Accepting, but feeling 'stuck'.	Same	Same – getting a bit less paranoid (A_2) as gets older. When less ill, feel need to hurry back (driving lesson, shopping).

APPENDIX 7.2: IMPACT ON FAMILY LIFE – ASTHMA GROUP

Participants	Aspect of personal life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
A_16, A_13 A_8	Impact on holiday or leisure experience	Has to check where surgery is, know medical support available, much advance preparation	Worries that asthma will worsen and no support available (A_16). Hassle to do all the preparation (A_8)	Same	Worries more when on holiday, esp. not knowing cause. Don't mind not having exotic holidays (A_13)
A_6 A_12 A_16 A_8 A_5 A_11 A_13 A_15	Impact on holiday or leisure experience	Whole family restricted in location of outings (e.g. zoo, horseriding), or holiday destination	Disappointing (A_6, A_8). Troublesome (A_15). Not bad (A_16, A_11, A_13). Other family members went to different holiday destinations (A_5)	Same (A_12, A_8, A_11)	Continues to be disappointed about restricted holiday destinations (A_12, A_8). Feels missed out on holidays together as a family. (A_5) Don't mind (A_11)
A_6 A_4 A_9 A_7	Impact on holiday or leisure experience	Sometimes child is unwell, so rest of family can't go out.	Cancel plans. Siblings are accepting and supportive, sometimes frightened.		
A_8	Impact on eating out as a family	Rarely eat out in restaurants.	Worries about allergy risk, mother disappointed	Starting to eat out more	Father feels very positive about this, mother still worried.
A_11	Impact on enjoying cooking at home	Unable to cook certain foods at home (fish and eggs allergy risk)	Enjoys fish and partner is good cook, but can't cook these in the home – disappointed.	Same	Same

APPENDIX 7.3: IMPACT ON PERSONAL LIFE – DIABETES GROUP

Participants	Aspect of personal life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
D_4	Sleep	Getting up at night to check blood sugar	More preoccupied with it	Still does it	Perception of it being more routine (but husband thinks she is edgy and anxious night-times)
D_12	Sleep	Get phone calls during night when child at friends'	Never feeling like they have a complete break	Same	Same
D_2	Sleep	Waking at night to check blood glucose and give food	Feeling this is abnormal parent behaviour, used to panic if child wouldn't eat when woken.	Not discussed	Not discussed
D_4	Vigilance and monitoring	Feeling of being constantly 'on call' / mobile always switched on	Feeling of being a 'major' effect on life	Same	Same – husband thinks she is 'like a cat on a hot tin roof' at night.
D_12, D_13	Vigilance and monitoring	Feeling of diabetes taking over one's life	The opposite is impractical if conscientious parents	Same	Same
D_6	Vigilance and monitoring	Does treatment and then tries to forget about it.	Doesn't think about the diabetes if she can help it – not a big deal.	Same	Uses mobile phone and has it switched on in case of problems– not previously. Was reluctant to do this as it reminded her of reason, but recognised it was easier.
D_8	Time, effort and features of treatment	High level of preparation needed when going out. Activities time consuming	Like having a baby again, thinking in advance.	Same, but has takes fewer items with them. Extra time for chemist and shopping trips.	Same, feels life is not as spontaneous as it was, needing to be prepared for unpredictable events. Time consuming in always going to chemist or food shopping, as have to read ingredients.

Participants	Aspect of personal life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
D_15	Time, effort and features of treatment	High level of preparation needed	Bad experience of not being prepared, and child became ill.	Same, but more prepared than previously	Now being more prepared allows for opportunities for coping with unpredictable events
D_3,	Time, effort and features of treatment	High level of preparation when going out	Like having a baby again. Become bolder in restaurants.	Same	OK, because 'you'd do anything'.
D_5, D_6, D_13, D_14	Time, effort and features of treatment	High level of preparation when going out	As when children were babies (all)	Same (all) When not prepared, disruptive (D_13)	Same (all) Had to disrupt visit due to forgetting insulin. Starting to learn to cope with it. Trying not to let it rule lives. (D_13)
D_2, D_7	Time, effort and features of treatment	High level of preparation and planning for activities	Have to be very organised (both). Become bolder in restaurants, felt constrained, less carefree (D_2).	Less regimented (D_2)	Learning to do most things with enough planning. Life pretty normal due to change in insulin regime, and child older. Looks at positive side, child is healthy. (D_2)
D_6	Time, effort and features of treatment	Minimal impact on time and effort – do the same things as others (e.g. taking food, water, blood testing kit etc).	Just have to think things through a bit. Uses mobile phone and has it switched on – not previously. Was reluctant to do this as it was reminded, but recognised it was easier.	Same, says diabetes diagnosed at time when was doing those things anyway at age 2, plus younger children so needs prep anyway.	Determined never to use diabetes as excuse not to do things, just might be awkward. Just 'pissed off' or 'bit of a pain' to do this. Gets cross with self if blames diabetes.

Participants	Aspect of personal life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
D_4	Working life	Quality of experience at work. Offered a job in London. Husband became self-employed, so could be at home.	M-Worry about child whilst at work, whether OK at nursery. M-Didn't take better paid job in London as too far away.	Yes	Less worry, as school matron calls whenever concerned (about monthly)
D_12	Working life	Having to take time off work when child unwell.	Feels has to always explain why off work to people that don't understand.	Same	Same, has to make up hours. Feels self-employed husband doesn't have this stress as no need to explain to everyone.
D_3	Working life	Job choice	Took pt job as TA in child's school, helped to be more available.	Same	Feels work are supportive and let her go when she needs to support child at school or take to clinic.
D_7	Working life	Having to take time off work when child unwell.	Missed working hours if child unwell or to attend clinic.	Same	Same. Gets telephoned at work by school. If had to leave work early, not a problem.
D_2	Working life	Working hours, quality of work experience	Early on, childminding problems so had to stop work. Resented it.	Now works part-time	Wouldn't work more hours, as know it wouldn't be possible as have to be 'on call'. Don't resent it now, but difficult to juggle child care.
D_10	Working life	Had job in child's school	This was helpful, easier being with him, but child didn't like it. Feels wouldn't have coped so well if just being at home.	School where parent worked closed, and now works part time elsewhere.	Had wanted job in child's new school or diabetic clinic, but thinks child wouldn't have liked this.
D_8 (M)	Working life	Hadn't worked before	Not due to diabetes	Still doesn't work	Own choice

Participants	Aspect of personal life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
D_9	Working life	Having to use annual leave for clinic appointments. Initially didn't have good childminder.	Feels had to save up annual leave days for this kind of thing. Initially felt a bit lost.	Now child older, can go to clinic herself. Had good childminder in later years.	Feels this is a nice relief that child can go to clinic on own, so doesn't need time off work. Felt lucky to have someone knowledgeable about diabetes. Felt no worries at work.
D_16	Working life	Couldn't cope with working full time due to child's diabetes	Working hours significantly reduced after diagnosis	Same	Considered increasing to full time, but felt wanted to be available for son, most important thing. It's OK, but misses social side of work. 'Best for us'.
D_5	Working life	Mother took job in school as dinner lady at diagnosis. Father self-employed so able to work flexibly if need time off.	Wanted to keep an eye on child at mealtimes, make sure he was eating lunch. Father uses annual leave for clinic appointments.	Same	Staff come to find her if child seems unwell. Children like her working in the school. Father doesn't mind taking annual leave for clinics, as feels important to be involved.
D_15	Working life	Initially worked in nursery where child was.	Child cared for in different section, but could check on him. Staff not competent, child became unconscious. Felt very frightened.	Gave up work due to added stress of potential health risks to child, and also not financially better off.	Better that doesn't work.
D_6	Potential working life	Not worked since having children	Hadn't intended to work, so no difference	Had considered working	Recognises would realistically be difficult, but don't mind. Wouldn't want to let someone down.

Participants	Aspect of personal life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
D_1	Potential working life	Not worked since having children	Hadn't intended to work, so no difference	Would consider work	Couldn't work as needs to be 'on call'. Doesn't mind not working.
D_13	Potential working life			Feels unable to work	Would love to work but feels need to be 'on call'.
D_11	Potential working life	Didn't return to work, having just stopped	Felt it was more important to be with diabetic child		
D_12	Going away with partner or spending time with partner or friends	Limited opportunities, partly due to childcare	Feels very resentful, but tries to console self by reminding self child could be worse.	Same, but more recently a teacher offered to babysit, but haven't used this yet.	Feels at disadvantage as little extended family. Feels would like to be able to discuss emotional side of experience with friends or family, but have no one close enough to do this with. Resentful of not having free time as couple or individuals.
D_3	Going away with partner	Never went away together	Not discussed	Planned but then cancelled weekend away	Still feels too worried to leave child, related to concerns re stability of diabetes; feels it is a shame. Doesn't want experience to be spoilt by being phoned up all the time. Feels lack of confidence, hopes to get over these feelings.
D_11	Going away with partner	Went away on a couple occasions for the weekend	A couple of occasions, child's aunt babysat, but child became unwell when grandparents looked after on other occasion.	Grandparents now frightened to look after him again. But child's aunt and mother's friend will do so.	Pleased able to have a break

Participants	Aspect of personal life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
D_10	Going away with partner	Went away once as a couple for the weekend	Didn't work out well – child was ill and grandparents had difficulty – felt guilty.	Has never gone away since due to worry	Thinking of doing this soon.
D_10	Socialising / going out with friends	Out less with friends than other parents with same age children	Would have gone out more if child not diabetic. Bit regretful. Also, experience of being out affected by worry.	Same, leaves parties early to get home, need to inject etc.	Same, on phone continually to check child OK. Have to be 'sensible'. Bothers parent that always in back of mind when out, never forgetting, always needing reassurance that child's OK. Weddings difficult when not routine.
D_8	Socialising / going out with partner or friends	Did not go out in evening with friends	Probably wouldn't have anyway	Mostly same, e.g. will leave for 1-2 hours	Only once left child in evening with godmother. Feels people are reluctant. Doesn't enjoy experience due to worry, checking phone.
D_14	Going away with partner for weekend	Hadn't gone away for weekend as couple for 14 years	Most people will not babysit for a diabetic child. Too much for others with child's poor diabetes control, too big responsibility	Now has an offer of babysitting from a friend who is recently became a paramedic	Have opportunity but don't know what to do. Would feel child would be in good hands.
D_1	Going away with partner for weekend	Has never been away	Can't do this because nobody would give injection	Same	Same
D_5	Socialising/going out with friends	Rarely go out in evenings	No babysitters, and family not capable	Go out sometimes but only around injection times	Nobody can cope with giving injections. Leaves child only for couple of hours with grandmother.

Participants	Aspect of personal life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
D_16	Socialising / going out with partner or friends	Stayed in more than previously.	Not eager to go out as feel need to be 'on call'	Starting to get 'back to normal'	Still reluctant to go out, but getting less worried as child getting older.
D_6	Socialising / going out with friends	Goes out with friends as before	Takes child with her if no childcare. That's fine, and a treat to have child on her own.	Same	Diabetes never stops her doing anything. Looks at positive side – e.g. advantage of jumping to front of queue. If stays overnight with female friends, husband looks after child.
D_9	Socialising / going out with friends	Didn't go out as didn't have babysitter and relatives couldn't cope.	Felt there were some social things she couldn't do. Sometimes felt a bit lost. When eventually went away for a week, very anxious, guilty and phoning daily.	Now able to go away because child at age 16 is more independent and self-caring.	Feels comfortable about going away for a weekend.
D_7	Socialising / going out with friends			Can go out in evenings if child eaten and had injection, keeps phone on, but hard if child is in not in good control	Better than when younger.
D_15	Socialising / going out with friends			Can go out, but needs to organise around injection times. Does less when bad diabetes control.	Needs to make sure injection in advance, good instructions. Has sensible babysitter. On end of phone, no big deal if well controlled. At times of bad control, anxious and doesn't want to go far.

Participants	Aspect of personal life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
D_10	Parent's habits	Extra food shopping	Shopped every day, worried not having enough.	Same	Feels she has to have a lot of food in the house, but has become an obsessive food shopper – throws a lot away.
D_10	Parent's habits	Dietary change to more carbohydrates in family meals	Parent feels this has led to parent weight gain (self and husband).	Same	Same – having diabetic child has changed the way they eat.
D_8	Parent's habits	Dietary change, also eat out less in restaurants.	Father felt he needed to eat more healthily, a culture shock	Will eat in former way, but not when child can see it.	Not a big issue because can eat differently at work.
D_9	Parent's habits	Dietary change, so eats same as child.	Feels it is just healthy eating, found it harder than child to adapt to eating vegetables.	Same	Same, 'didn't happen overnight'
D_15	Parent's habits	Limited change, as ate healthily anyway	Always ate vegetables, so no problem	Same	Same
D_7	Parent's habits	'Child eats what we eat'	Formerly bought special food, e.g. cereal bars but not now	Does not perceive there to be an impact on own eating habits	(N.B. Child eats what parent eats, not specified if this is suitable for diabetic?)
D_15 D_14 D_7	Feeling weight of responsibility	Diabetes is always in the background	Influences life in general, 'got to be on the ball'	At times of bad control, greater sense of burden.	Feels stressed at that time, on edge.
D_12	Feeling weight of responsibility	Feeling of being older, more mature, more responsible	Contributes to feeling constrained by life.	Same, growing as a person	Family bereavements, loss of husband's job in addition to child's diabetes. Unsure what has shaped current feelings of growing as a person.

Participants	Aspect of personal life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
D_2 D_13	Feeling weight of responsibility	Activities of life all affected.	Feeling that nothing is ever the same, due to having to always make provision for diabetes.	Same	Same
D_1	Feeling weight of responsibility	Unable to be more than 15 mins away from school	Blames school for not taking responsibility. Feels life is very restricted.	Same	Same
D_14	Family planning	Terminated pregnancy shortly after child's diagnosis	Felt unable to cope, now couple feel guilty, that it was wrong	Still feel guilty	Seeking counselling
D_8	Financial impact	Extra expenses	Felt expensive to buy 'emergency' meals when out, cereal bars, medical bracelet, etc.	Same	Better as has disability allowance.
D_2	Financial impact	Extra expenses	Felt expensive to get other stuff like shoes on beach, food.	Same	Better as has disability allowance.
D_11	Financial impact	Extra expenses	Chose private school for better health monitoring. Whilst abroad, had extra expenses, but insurance.		

APPENDIX 7.4: IMPACT ON FAMILY LIFE – DIABETES GROUP

Participants	Aspect of personal life in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
D_12 D_4 D_13 D_3 D_15 D_5 D_14 D_11	Impact on holiday experience	Felt restricted in choice of holiday – location, facilities (D_12, D_5, D_14, D_11). Concerned about being on an aeroplane (D_4) Need to be very organised (D_3, D_15, D_5) Restriction due to child not being willing to eat unfamiliar food (D_11)	‘Muddled through’ (D_12) Too risky to go on plane (D_4) Need to find out where local hospital is etc. Needs to learn key words in language. (D_12, D_5) It’s fine to have to do all the preparation (D_3, D_5) Bit of a shame (D_11)	Chooses holiday in complex (near hospital) rather than preferred option of villa. (D_12, D_5) Doesn’t go on planes (D_4) Needs more planning (D_13, D_3, D_15, D_5) Need to learn key words in foreign language (D_5) Not a problem with food restrictions now (D_11)	Recognises that holidays different from otherwise, and that had to pay extra expenses due to special travel insurance. (D_12) Bit sad that always have to do these things e.g. where’s hospital? But pleased when it is successful, managed not to notice the diabetes too much - and gets better with experience (D_5)
D_10 D_14	Impact on holiday experience	Hard to manage holidays, blood sugars erratic.	Worried about whether would find shop or restaurant, worries about blood sugar, feeling like can never do anything out of the ordinary.	Did similar holidays after that, but this year went to America (D_10) Doesn’t go on holiday abroad due to poor blood glucose control (D_14)	Touring holidays – improved blood sugar and easier with experience. Although did this, still difficult. Recent holiday also difficult and a bit of a worry, but feels one learns as one goes along. (D_10)

Participants	Aspect of personal life in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
D_12 D_10 D_8 D_5 D_11	Impact on family outings	More planning needed (e.g. restaurant times). (all) Don't eat things in cinemas as previously (D_12) Late night family outing disrupts blood glucose (D_12)	Siblings accept this, eat peanuts instead. (D_12) Will have to plan carefully, e.g. for late night outings. Not able to be spontaneous (D_11)	Same Less problematic due to basal bolus (D_11)	Same Not a huge effect – (D_11)
D_13	Impact on types of leisure activity	Don't eat out in restaurants as family	Too hard to control.	Same	Same
D_8 D_13	Impact on enjoyment of leisure activity	Disruption of experiences (D_8)	If not prepared with equipment etc. can't stay at friends if ad hoc invitation. (D_8)	Staying with friends who don't eat healthily (D_8) Time together as family being disturbed by treatment regime etc.	It is a 'pain' when hosts don't eat healthily. When out, always checking for phone messages etc. Perhaps unnecessary sense of urgency, but must balance vs not caring. (D_8) Try not to let it rule family life, dominate it (D_13)
*D_6	Impact on enjoyment of leisure	Minimal impact, some positive	Makes sure doesn't affect family, finds solutions. Looks at advantages (e.g. going to front of queue)	Same	Same.

APPENDIX 7.5: RESPONSES OF SIBLINGS – ASTHMA GROUP

Participants	Aspect of sibling life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
A_12	School	Sibling and child went to a different (local) school. (A_12) Sibling has fallen behind in school work when brother in hospital (A_12)	Parent felt needed to be nearby if child had attack (and to collect sib also).(A_12). Upset at others not understanding (A_12)	Same	Same
A_5, A_6, A_5, A_9, A_12,	Skills and knowledge about disease and treatment	Siblings and others take on responsibilities for medical care	Accepting	Same	Same
A_14	Leisure activities	Mother believes swimming and healthy diet good for asthmatic child, so good for everyone in family.	Siblings now swim regularly and eat more healthily.	Same	Siblings don't notice changes, as are gradual. Believes lower asthma severity means no negative effect on siblings.
A_6, A_5	Leisure activities	Siblings didn't go to the zoo	Siblings didn't mind and were supportive	Fight about other things (A_6)	
A_5, A_7, A_14	Time and attention given by parents – unequal treatment	Siblings often left alone with relatives. (A_5) Siblings are treated differently from sick child (A_5, A_7, A_14)	Siblings found it difficult being left – couldn't understand (A_5) Siblings believed they got less attention and were resentful of apparent preference (A_5, A_14) Siblings unaware of different treatment, no complaint (A_7)	Teen daughter smokes in house	Refuses to stop this.
A_9, A_10, A_13	Time and attention given by parents – equal treatment			More time with ill sibling, but treat them the same (A_13). No sibling rivalry (A_12)	Siblings think treated unequally, but parent does not agree (A_9, A_10).

Participants	Aspect of sibling life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
A_12, A_13	Response to stressor, e.g. hearing about risks of death (A_13) or witnessing bad asthma attack (A_12)			Has become more 'clingy or 'cuddly' with parent and sibling	Sibling is anxious about possible loss of asthmatic sibling

APPENDIX 7.6 RESPONSES OF SIBLINGS – DIABETES GROUP

Participants	Aspect of sibling life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
D_1, D_3, D_4, D_8, D_11, D_12	Hearing of diagnosis (D_1, D_3, D_4, D_8, D_13) or witnessing hypo (D_11, D_12)	Distressed	Worried about sibling, but coped well (all). Became more protective of sibling (D_1, D_3, D_12)	Sometimes recalls distressing / frightening experience (D_12)	Still talks about experience, parents believe need chance talk about it with others besides parent (D_12) Feels sorry for sibling, and has become closer, protective (D_3, D_12) Now treats sibling as before, doesn't let sibling use diabetes as excuse (D_8)
D_12 D_10 D_8 D_3 D_9	Food and mealtimes	Mealtimes were more structured. Some foods changed (D_8, D_3, D_9)	Eat at regular times and don't skip meals. No sweets in the house. (D_12)	A little more flexibility on family mealtimes, with basal bolus. (all) Still no sweets in house. (D_12)	Siblings have diet suitable for diabetic when eating at home, and eat more regularly (D_8, D_3)
D_6 D_15 D_7	Food and mealtimes	Mealtimes and diet unchanged	No changes needed to family diet	Sibling is careful what she eats around diabetic sibling (D_12)	It's difficult (D_12)

Participants	Aspect of sibling life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
D_12	Treats – equal restrictions	Sibling not allowed snack when diabetic child is.	Sibling had some resentment. Parents find it difficult to not to allow snack.	Same	Same
D_6, D_15	Treats – equal restrictions at times	Parent restricts all children from having snack if child's blood sugar too high	Tries to give different reason – too close to dinner, not use diabetes as excuse. (both) Also, gives alternatives to child with diabetes, and has 'sweet tin' for controlled use of sweets. (D_6)	Same	Same
D_2, D_5, D_7	Treats – unequal restrictions	Sibling allowed sweets when not in presence of diabetic sibling (D_2) Sibling allowed sweet things any time (D_5, D_7)	Sibling accepts this (D_2) Sibling doesn't feel left out (D_7) Uses knowledge of snack routine to ask for biscuits at same time as sibling (D_5)	Same	Same
D_10	Treats - equal then unequal restrictions	Originally stopped sweets for sibling	Sibling was resentful	Later allowed sweets for sibling	Sibling now older, so less relevant

Participants	Aspect of sibling life affected in past or present	Impact in past?	Previous feelings or actions about it	Impact in present?	Present feelings or actions about it
D_1, D_2, D_3, D_4, D_5, D_6, D_10, D_12, D_15, D_16	Skills and knowledge about disease and treatment	Siblings injected selves and took own blood test (D_12) Observes child injecting self (or parent injecting) or other treatments	Parents wanted them to experience what sibling experienced. Sibling didn't want to inject self at the time (D_12) Can be competent (all), feels sympathetic to sibling (D_6, D_10, D_12), or only when in a 'good mood' (D_15) Helps with treatment (all)	Help with treatment (all), volunteer not to have sweet things if their sibling can't have it (D_16)	Parent feels siblings are 'mature' & having responsibility is good. Now sibling doesn't mind having done injections and BMs on self, but doesn't like watching sibling inject (D_12) Sometimes questions parents' decisions about treatment (D_3) Sometimes sibling actions detrimental to child's health (D_15)
D_12	Time and attention given by parents – equal treatment	Parents believe they give equal attention	Parents believe they treat children equally	Same	Same
D_4, D_13, D_14, D_15, D_16	Time and attention given by parents – unequal treatment	Had unequal attention	Bothered sibling that had unequal attention (D_4, D_13, D_14, D_15)	Same (all) Observes sibling non-compliance with diet (D_14)	Has come to terms with it, but thinks sibling uses diabetes as excuse for bad behaviour (D_4). Complains about unfairness (D_13, D_15), craves more attention (D_13, D_14, D_15)
D_10, D_15	Different levels of 'protection' of sibling and diabetic child	Sibling perceives parent over-protection of diabetic child	Sibling tells parent they 'mollycoddle' diabetic child	Same	Tells parent they should allow child more independence (D_10) Resentful, fights with sibling parent believes this is due to jealousy, and it's getting worse (D_15)
D_3	Different levels of 'protection' of sibling and diabetic child	Sibling has awareness of health risks (older sibling)	Sibling question parents' treatment decisions, thinks parents take too many risks	Same	Same

APPENDIX 7.7 - FEELINGS ABOUT FAMILY RELATIONSHIPS – ASTHMA GROUP

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
EXTENDED FAMILY RELATIONSHIPS																
<i>Positive aspects</i>																
‘Pulling together’						√							√		√	
‘Work together’ / cooperate (but not about asthma)			√													
Grandparents more involved		√				√	√						√		√	
Show empathy and understanding, more protective		√				√					√					
Some members always supportive (whether crisis or not)– offer practical and / or emotional help		√				√	√				√				√	
Some or all only supportive (practical and/or emotional) if there is a crisis		√	√													
Relative changes lifestyle (stop smoking)		√														
Become ‘health promoters’ with relatives		√														
<i>Negative aspects</i>																
Some or all not capable, so not able to support adequately			√					√								
Some or all not supportive or understanding		√						√						√		

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
Grandparent(s) worry excessively, panic		√		√												
Grandparent 'spoils' child																
Tension with and some criticism from relatives				√												
'CORE' FAMILY RELATIONSHIPS																
<i>'How we cope'</i>																
<i>Positive aspects</i>																
'Pulling together'												√			√	
Look out for each other, be loving, empathetic, practically helpful				√			√					√		√		
Be positive, e.g. 'we can cope'					√						√	√		√		
Be accepting, get on with it, make it routine					√					√		√		√		
Don't let in run family's life												√				
Read a lot about illness and treatment, share information with each other																√
'Play it down'															√	
Be more healthy (e.g. improve fitness)										√						
Try to listen and communicate well, encourage child to 'speak up'				√												
<i>Negative aspects</i>																
Worry about being alone (lone parent)			√													
Harder to be patient with child when alone; little extended family involvement			√													

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
Focus on the child as most important					√											
One or more core family members 'don't understand'					√											
Changes in relationships connected with illness																
<i>Extended family</i>																
<i>Positive aspects</i>																
'Bonds' together family members that understand		√					√									
More aware of how 'precious' all children in family are – changed feelings of parent									√		√					
<i>Negative aspects</i>																
More arguments with family members that don't understand		√														
Grandmother spoils child more							√									
<i>Core family</i>																
More emotionally demonstrative with each other, all feel closer to each other							√					√			√	
Only mother is intensely close to child					√		√									
Family 'pulls together' when in crisis														√		

APPENDIX 7.8 - FEELINGS ABOUT FAMILY RELATIONSHIPS – DIABETES GROUP

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
EXTENDED FAMILY RELATIONSHIPS																
<i>Positive aspects</i>																
Grandparents more involved		√													√	
Some members always supportive (whether crisis or not)– offer practical and / or emotional help		√									√					√
Some or all only supportive (practical and/or emotional) if there is a crisis							√									
<i>Negative aspects</i>																
Some or all not capable, so not able to support adequately	√						√		√		√				√	√
Some or all not supportive or understanding	√						√		√						√	
Child ‘manipulates’ grandparent														√		
‘CORE’ FAMILY RELATIONSHIPS																
<i>‘How we cope’</i>																
<i>Positive aspects</i>																
‘Pulling together’ / being a team	√							√			√	√				
Trying to be a ‘community’ e.g. at mealtimes														√		

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
Be positive, e.g. 'we can cope' / count your blessings	√					√					√					
Don't blame diabetes for problems						√		√								
Recognise problems and can change			√													
Be accepting, get on with it, make it routine				√ (F)	√ (F)			√								
Read a lot about illness and treatment, share information with each other												√				
'Play it down'																
Be more healthy / be healthy					√											
Try to listen and communicate well, encourage child to 'speak up'	√															
Negative aspects																
Worry about being alone (lone parent)							√								√	
Focus on the child as most important; has caused problems, arguments				√			√									
One or more core family members 'don't understand'						√									√	√
Child's blood glucose levels affects how positive or negative the family feels							√					√				
Tension and communication problems due to competing needs within family														√	√	

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
Changes in relationships connected with illness																
<i>Extended family</i>																
<i>Positive aspects</i>																
Think about every child's individual needs	√															
<i>Core family</i>																
Initially, family focused around child, but when realised this, changed			√													
Focus on child, do whatever is best for them											√					√

APPENDIX 7.9: FEELINGS ABOUT PARENTING ROLE - ASTHMA GROUP

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Feelings about parenting in general</i>																
Feels alone at times as a parent / harder for them than others		√			√		√		√							
Feels positive when child overcomes difficulties, does something independently or copes well.				√				√								
Difficult to always to be positive for the child (who is negative).					√											
<i>Supportive / encouraging behaviours towards child</i>																
Concerned about poor effort at school, but have tried to ‘step back a bit’ and just encourage.								√								
Reassures child when more anxious, upset or ‘down’ (e.g. after recent hospitalisation) – not always effective if child can’t understand					√	√							√			
Tries to explain reasons for treatment in age appropriate way.					√											
Parent is assertive on child’s behalf/ is an advocate for child								√								

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Treating as special: Being very protective or not letting go</i>																
Parent believes they are over-protective, and worry about limiting child development.						√	√	√			√	√		√		
Parent feels upset at thought that child will have to cope alone as adult					√											
Parent restricts activities, believes child can't safely deal with risky situations, can't trust others to care.								√			√					
Parent restricts some activities (not to siblings); child accepts this.												√				
<i>Treating as normal: Trying not to overprotect</i>																
Trying to let child do things, as otherwise will hold child back		√	√							√						
Allow child to do what they can – don't overprotect. Feels maybe a bit hard on child, as pushes her to do what she can.				√												

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Treating as special: 'spoiling' compensating for restrictions or feeling sorry for child</i>																
Feels spoils child							✓									
Although badly spoiled when younger, now more able to be firm															✓	
<i>Treating as normal: not spoiling</i>																
Occasionally compensate for restrictions, but don't overcompensate								✓								
<i>Treating as special: Treating asthmatic child differently due to illness</i>																
Does not treat children equally – gives special attention to asthmatic child					✓		✓		✓					✓		
Feels more protective, feels closer than to other children					✓		✓		✓		✓			✓		
Grandparent tends to nag about medication, parent does sometimes, as child not very compliant															✓	
<i>Treating as normal: Treating children equally to siblings</i>																
Tries to treat children equally – no sibling rivalry												✓				

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Treating as special (uncertain attribution?): Child behavioural issue involving parenting response</i>																
Parent gives (or gave) into child's demands ('manipulation') (e.g. to sleep in parents' bed when wheezy)					√										√	
Parent tries to ignore argumentative behaviour, but sometimes wonders if caused by symptoms – hesitant re how to respond			√													
<i>Treating as normal: Child behavioural issue involving parenting response</i>																
Parent tried to be firm (e.g. about food), but interactions unpleasant, conflicts and rows previously.								√								
Parent uses reward system to promote desired behaviour (e.g. sleeping).							√								√	√
Uses punishment to promote desired behaviour (but inconsistent)															√	
Feels have less influence over child's behaviour due to age as teenager															√	√

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>Feelings about impact on siblings, parenting responses</i>																
Sibling jealousy at perceived unequal treatment – caused friction					✓									✓		
Siblings apparently treated equally – no rivalry												✓				
Siblings apparently unaware of unequal treatment (as parent gives treats in other children’s absence)							✓									

APPENDIX 7.10: FEELINGS ABOUT PARENTING ROLE - DIABETES GROUP

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Feelings about parenting in general</i>																
Feels alone at times as a parent / harder for them than others, or hard to know how to give emotional support		√		√							√				√	
Hard to make decisions about what to allow, due to need to balance upset due to restrictions against negative consequences for blood glucose control								√			√					
Feels positive when child overcomes difficulties, does something independently or copes well.	√															√
Worry about being accused of not caring (if blood glucose not well controlled) or making mistakes			√		√								√			
Wishes child could have normal childhood															√	
Feels children unfairly blame parent for things that go wrong															√	

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Supportive / encouraging behaviours towards child</i>																
Parents injected selves to empathise with child			√									√				
Concerned about poor effort at school, but have tried to 'step back a bit' and just encourage.										√						
Reassures child when more anxious, upset or 'down' – not always effective if child can't understand			√						√		√		√			
Tries to encourage child's openness about disease	√							√		√		√				
Encourages appropriate eating by child, but struggles with child's reluctance				√						√						
Tries to explain reasons for treatment in age appropriate way – e.g. understanding risks								√			√					
Tries to teach child to be more responsible, when less responsible than age would suggest					√		√				√				√	
Tries to get child to talk about his problems, but this is difficult												√				
Avoids eating sweet things in front of child, as that would be cruel								√								
Advocates for child – e.g. taking action to stop bullying at school, or advocating for equal treatment by school	√	√						√								
Tells child they are brave to put up with teasing at school about diabetes														√		

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Treating as special: Being very protective or not letting go</i>																
Parent believes they are over-protective, but concerns about limiting life opportunities or development	√		√		√			√	√	√	√	√	√		√	√
Parent feels upset at thought that child will have to cope alone as adult				√				√					√			
Parent restricts activities, believes child can't safely deal with risky situations or can't trust others to care.		√										√				√
Parent restricts some activities (not to siblings); child accepts this.										√						
<i>Treating as normal: Trying not to overprotect</i>																
Trying to let child do things, as otherwise will hold child back	√					√							√			
<i>Treating as special: 'spoiling' compensating for restrictions or feeling sorry for child</i>																
Feels spoils child					√										√	
<i>Treating as normal: not spoiling</i>																
Occasionally offer sweets in controlled way – child accepts this				√	√			√								
<i>Treating as special: Treating diabetic child or feeling differently than towards siblings</i>																
Does not treat children equally – gives special attention to diabetic child				√	√										√	

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
Feels less attached to diabetic child					√ (F)											
<i>Treating as normal: Treating children equally to siblings</i>																
Tries to treat children equally (some sibling resentment, e.g. sweets restrictions or sib feeling not getting same attention)												√	√			
Tries to treat children equally – when siblings have sweets, offers alternative to diabetic child	√					√										
Tries to treat children equally – e.g. all have same chores	√															
<i>Treating as special (uncertain attribution?): Child behavioural issue involving parent's uncertain response</i>																
<i>Uncertain</i> how to deal with difficult behaviour as don't know cause (puberty? diabetes? non-acceptance?)							√		√				√		√	
Parent <i>gives into child's demands</i> ('manipulation') (e.g. bad behaviour might be due to hypo or might not – maybe normal development?)				√				√						√		
More argumentative with diabetic child than sibling – due to being teen or diabetes?											√					

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Treating as special: Child behavioural issue involving parenting response</i>																
Parent lets child choose what they will eat. (Child is fussy eater, and parent feels compelled to give them what they want due to worries about hypo)		√		√ (M)										√		
Parent does not allow child to 'get away with' more because of diabetes	√															
Parent allows child to 'get away with bad behaviour' more than sibling					√									√		
Parent tends to nag about medication or treatment, as child not very compliant or is forgetful (both dislike this) (N.B. Protective behaviour)							√	√	√		√		√			
<i>Treating as normal: Child behavioural issue involving parenting response</i>																
Parent tried to be firm either about food or other discipline issues		√		√ (F)	√	√								√	√	
Parent has raised expectations of compliant behaviour due to child getting older (but not happening).							√				√					
Parent uses reward system to promote desired behaviour (e.g. doing injections).							√	√						√		

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
<i>Feelings about impact on siblings, parenting responses</i>																
Sibling resentment at perceived unequal treatment – e.g. diabetic sibling gets away with more ‘bad behaviour’ as parent uncertain of cause				√											√	
Parent thinks siblings treated equally, but sibling has expressed resentment at extra attention							√									
Parent is stressed due to diabetic child’s non-compliance, and so parent shouts at siblings							√									
Parent concerned that sibling is trying to compensate for sibling’s misbehaviour (worried about him trying to be a ‘paragon’)														√		

APPENDIX 7.11 - FEELINGS ABOUT PARTNER RELATIONSHIP – ASTHMA GROUP

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
<i>MOTHER IS RESPONDENT</i>		<	<	<	<	<	<	<		<	<		<		<	<
Ex-partner not involved – no contact (separated or divorced)			<	<		<									<	
Husband left her and child (before diagnosis) – found this difficult, now feels closer to child because of this (compensates)						<										
Ex-partner sometimes involved		√			√											
Couple divorced (after diagnosis) – believes child’s illness contributed - mother is very close to child		√			√											
Does not believe ex-partner is competent in illness management – this is ‘difficult’ / adds stress					√											
Believes ex-partner is competent in asthma care – this is helpful. (When married, did not share enough responsibility, contributing to breakup, in combination with financial stress)		√														

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
Current partner is involved (living in household)		✓					✓		✓	✓	✓	✓		✓		✓
'Divided responsibilities' – father not involved in asthma management									✓	✓		✓				
'Divided responsibilities', but father sometimes gives medication etc.		✓									✓					
Same responsibilities (shared)							✓									✓
Focus together on child's need and illness management. Although both feel stressed, sharing helps each other.																✓
Generally, couple agree with each other about illness management – usually does not cause stress in relationship																✓
Couple sometimes disagree with each other about illness management and / or have different ways of coping – sometimes source of tension, but recognises and tries to resolve							✓									
Similar personality and abilities of couple help them to support each other																✓
Individual differences of husband (more calm) helps wife to cope							✓									
Has experienced 'pressure' on marriage relationship due to child's illness												✓		✓		

Child age (years)	10	4	16	14	15	13	5	12	10	11	7	8, 11	2	16	13	4
Participant number	A_1	A_2	A_3	A_4	A_5	A_6	A_7	A_8	A_9	A_10	A_11	A_12	A_13	A_14	A_15	A_16
Good communication has helped relationship – need to make allowances												✓				
Partner is minimally involved – works away from home	✓													✓		
<i>BOTH MOTHER AND FATHER ARE RESPONDENTS</i>								✓					✓			
Same responsibilities (shared)								✓								
‘Divided responsibilities’, but father sometimes gives medication etc.													✓			
Generally, couple agree with each other about illness management – usually does not cause stress in relationship								✓					✓			
Couple sometimes disagree with each other about illness management and / or have different ways of coping – sometimes source of tension, but recognises and tries to resolve								✓					✓			

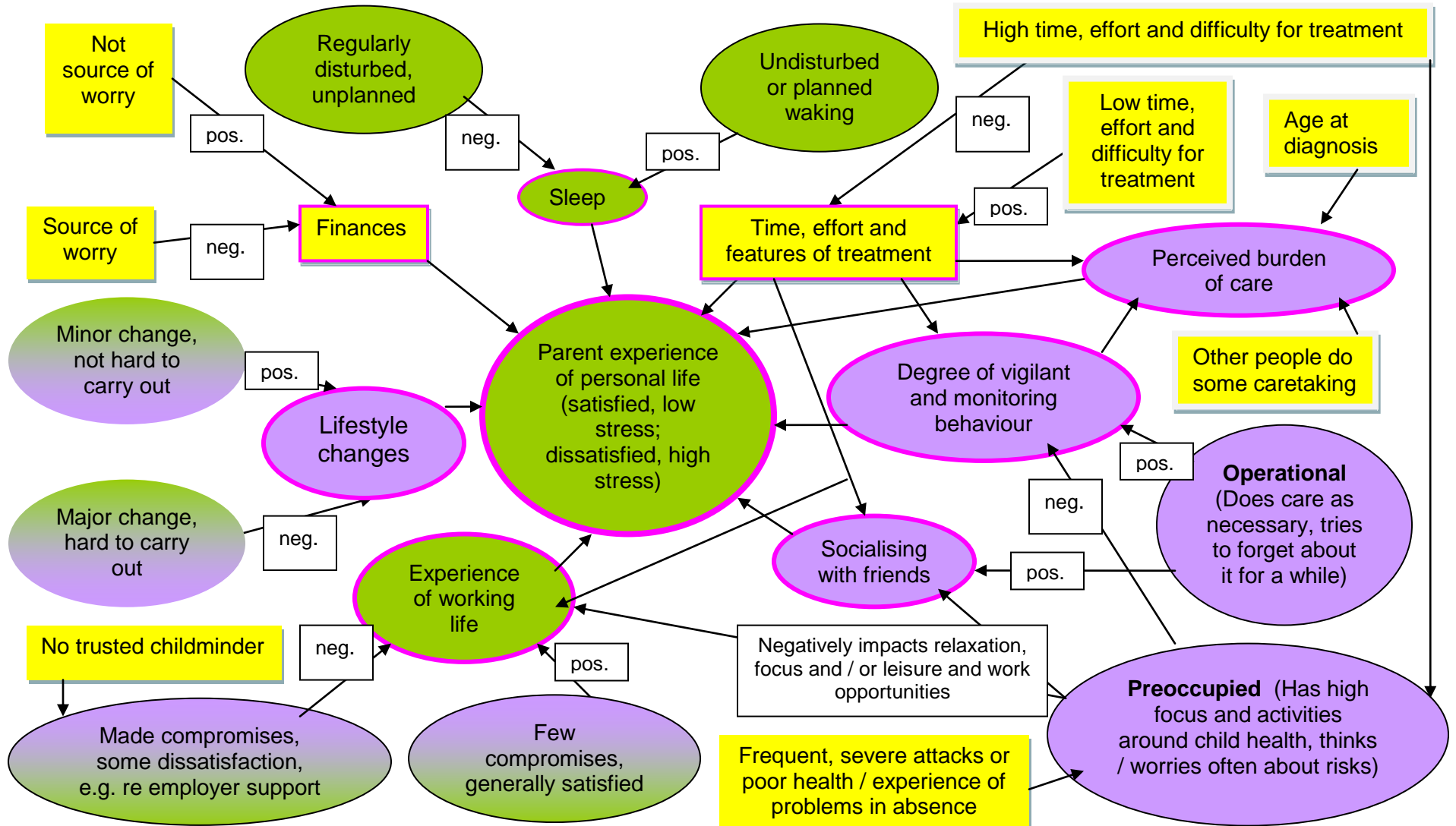
APPENDIX 7.12 - FEELINGS ABOUT PARTNER RELATIONSHIP – DIABETES GROUP

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
MOTHER IS RESPONDENT		✓	✓			✓	✓		✓	✓	✓				✓	✓
Ex-partner not involved – no contact (separated, divorced or deceased)							✓									
Ex-partner minimally involved – little contact (separated or divorced)									✓						✓	
Does not believe ex-partner is competent in illness management – this is ‘difficult’ / adds stress									✓							
Current partner is involved with child (living in household)	✓	✓	✓			✓				✓						
‘Divided responsibilities’ – father not involved in asthma management	✓	✓														
‘Divided responsibilities’, but father sometimes gives medication etc.						✓				✓						
Same responsibilities (shared)			✓													
Generally, couple agree with each other about illness management – usually does not cause stress in relationship										✓		✓				
Couple sometimes disagree with each other about illness management and / or have different ways of coping – sometimes source of tension, but recognises and tries to resolve			✓			✓						✓				

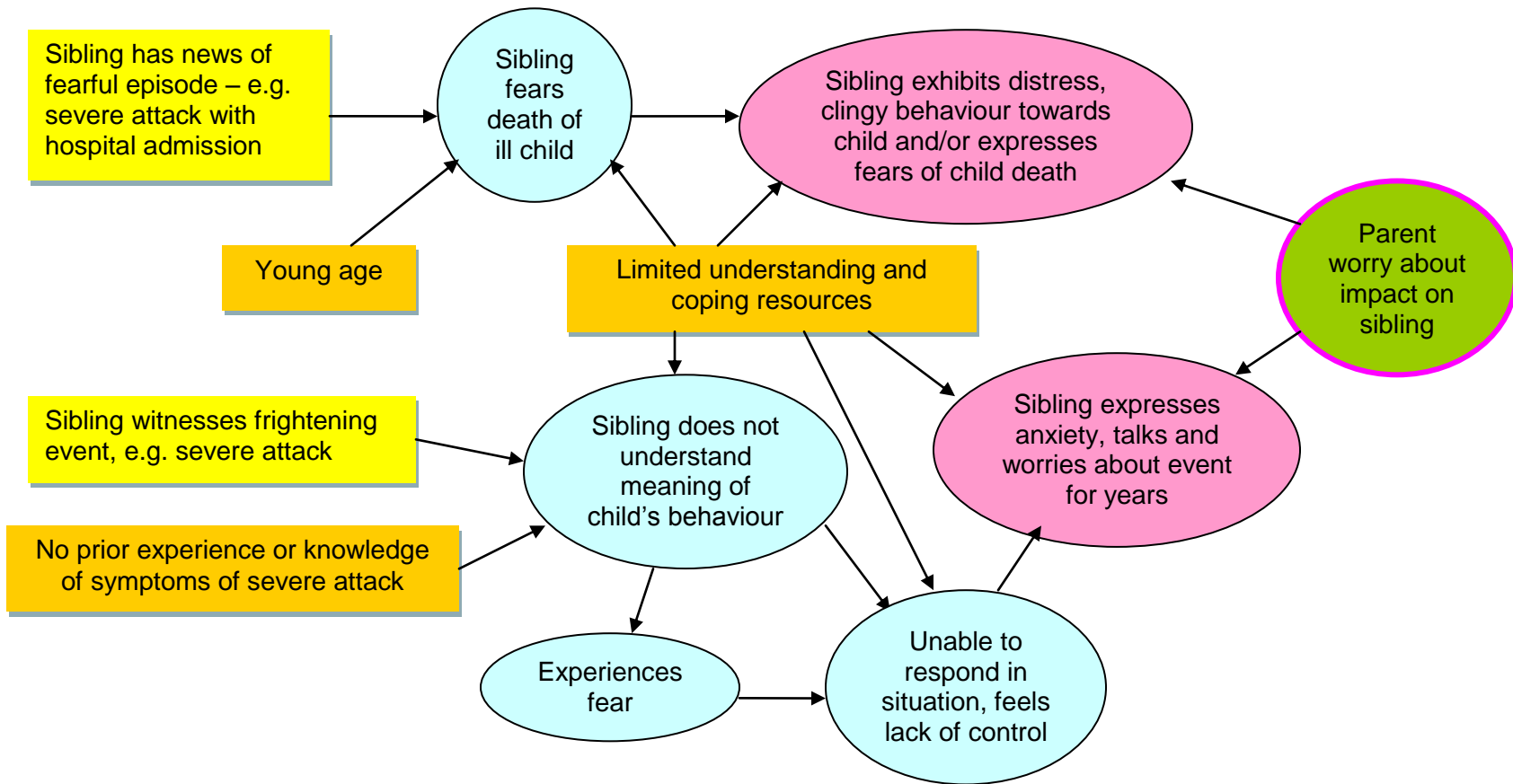
Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
Have experienced relationship difficulties, but 'nothing to do with diabetes'	√															
Individual differences of husband (e.g. more calm) helps wife to cope		√								√						
Individual differences make relationship more difficult (when disagreeing)			√			√										
Has experienced 'pressure' on marriage relationship due to child's illness			√													
Mother blames self for marital tension, should have used common sense more			√													
Partner is minimally involved or not involved in diabetes care											√					√
Mother feels unsupported by partner – gives reason e.g. long working hours, mental illness – feels less supported											√					√
BOTH MOTHER AND FATHER ARE RESPONDENTS				√	√			√				√	√	√		
Same responsibilities (shared)				√	√			√				√	√	√		
Generally, couple agree with each other about illness management – usually does not cause stress in relationship												√		√		

Child age (years)	9	8	13	6	10	8	15	13	16	16	15	10	12	13	8	15
Participant number	D_1	D_2	D_3	D_4	D_5	D_6	D_7	D_8	D_9	D_10	D_11	D_12	D_13	D_14	D_15	D_16
Couple sometimes disagree with each other about illness management and / or have different ways of coping – sometimes source of tension, but recognises and tries to resolve					√			√								
Stress with child non-compliance has created unpleasant ‘atmosphere’ affecting partner relationships								√						√		
Couple sometimes disagree with each other about illness management and/or have different ways of coping – causes conflict, not resolved				√												
Wife reports strain on relationship due to disagreements about eating				√												
Husband feels neglected due to too much attention on diabetic child				√												
Couple report that stress of caring for child affected time available to work on own relationship														√		

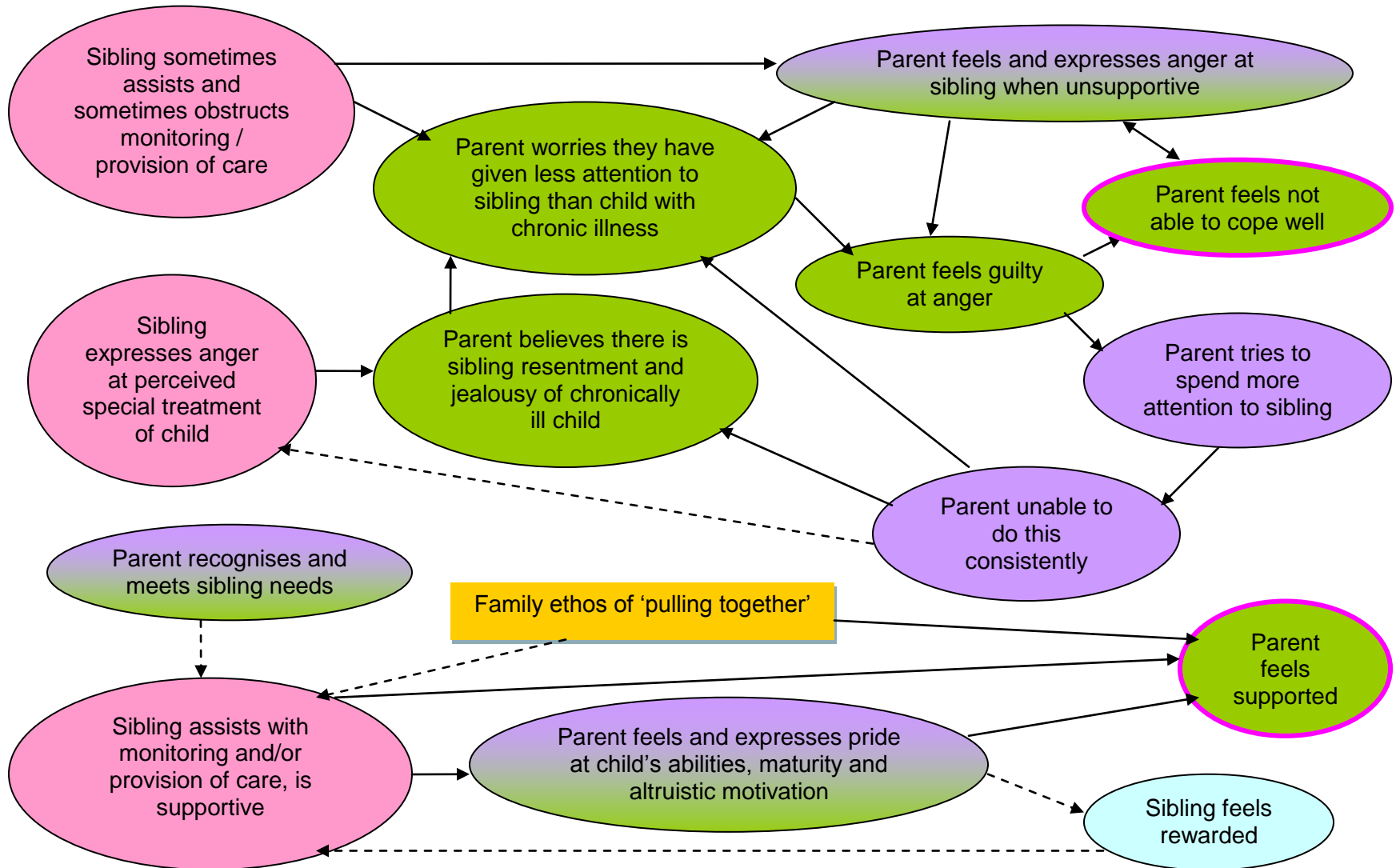
Appendix 7.13: Schematic Diagram 25: Impact on parents' personal life – what helps and hinders (both groups)



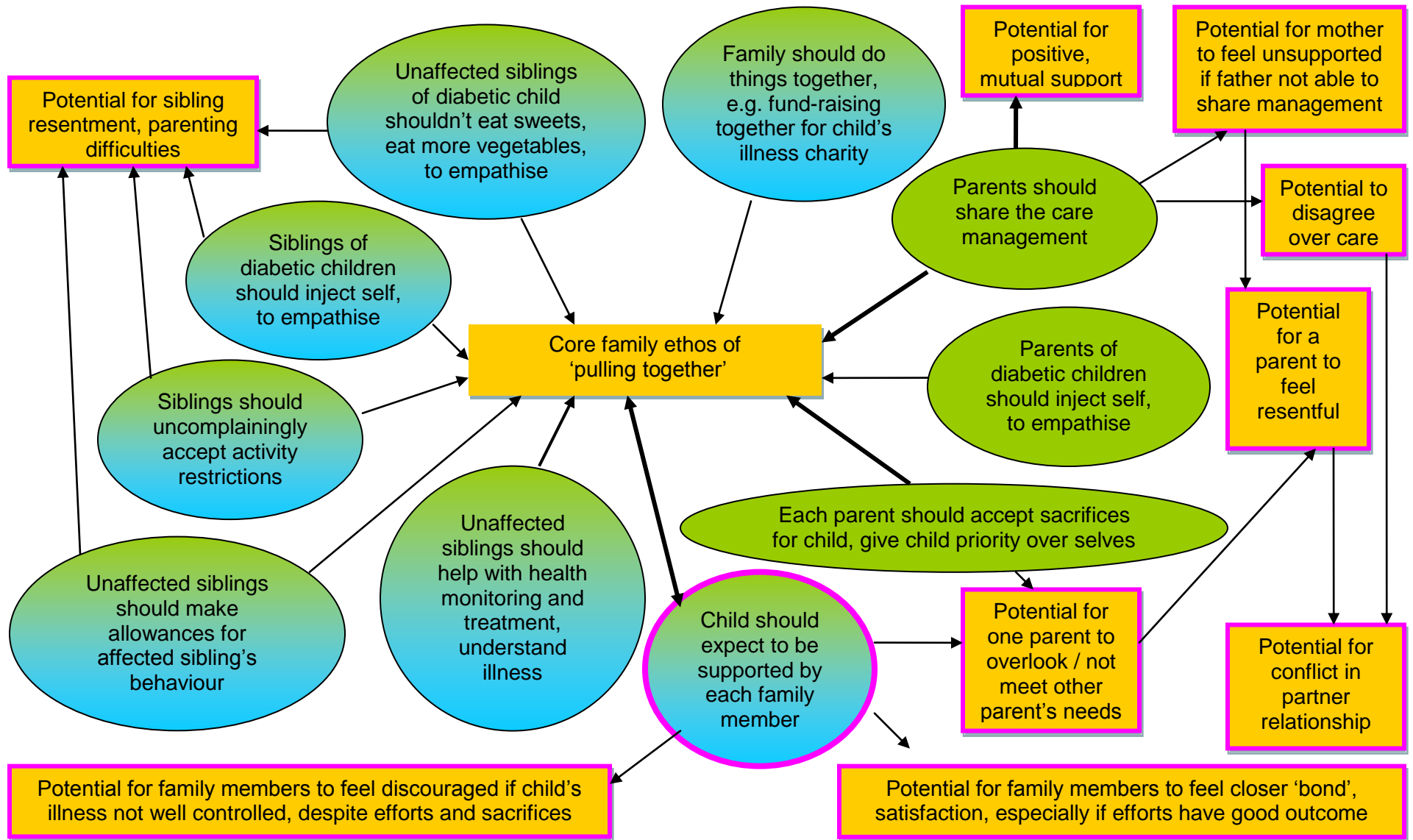
Appendix 7.14: Schematic Diagram 26: Impact on siblings – witnessing or hearing about atypical, serious episodes (both groups)



Appendix 7.15: Schematic Diagram 27: Sibling responses in care management context – both illness groups

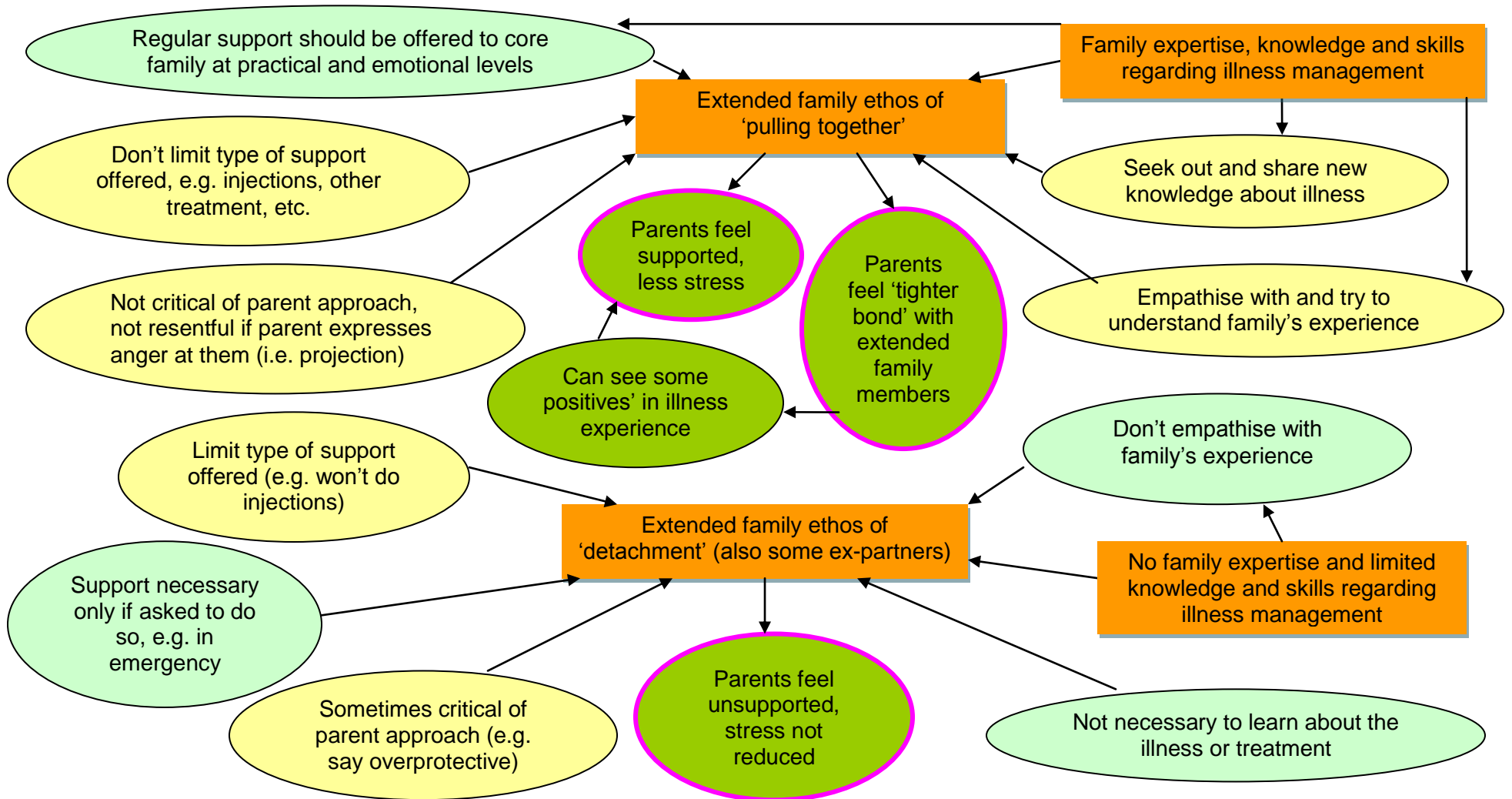


Appendix 7.16: Schematic Diagram 28: Family ethos of 'pulling together' – positive and negative aspects (both illness groups)
 (N.B. not all components always present, different pathways may be followed, different outcomes)

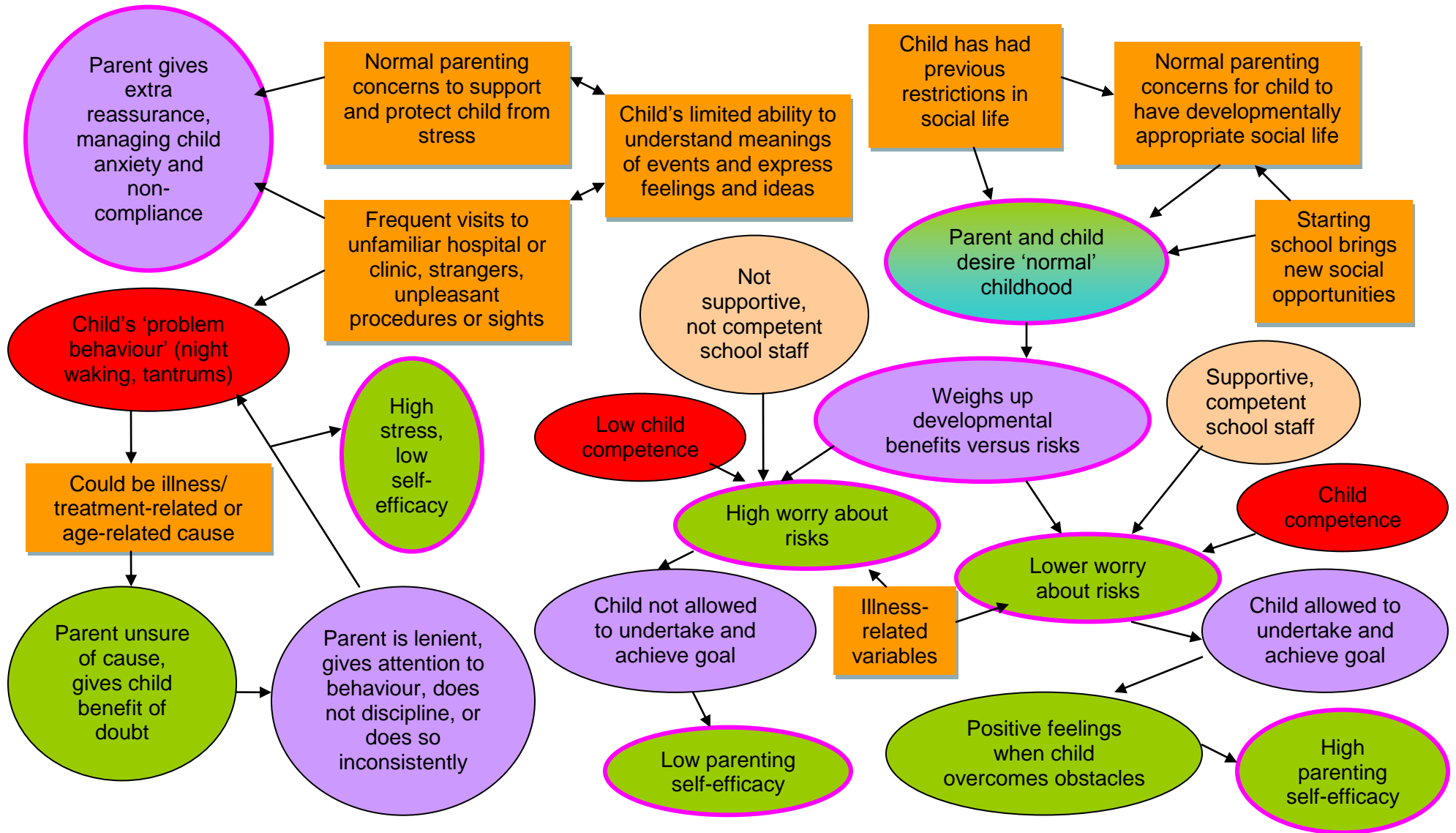


Variation of above: Pulling together, but chronically ill child not at centre, members accept they can be different – e.g. alright for siblings to have sweets, ill child has alternative – less resentment of sibling of chronically ill child.

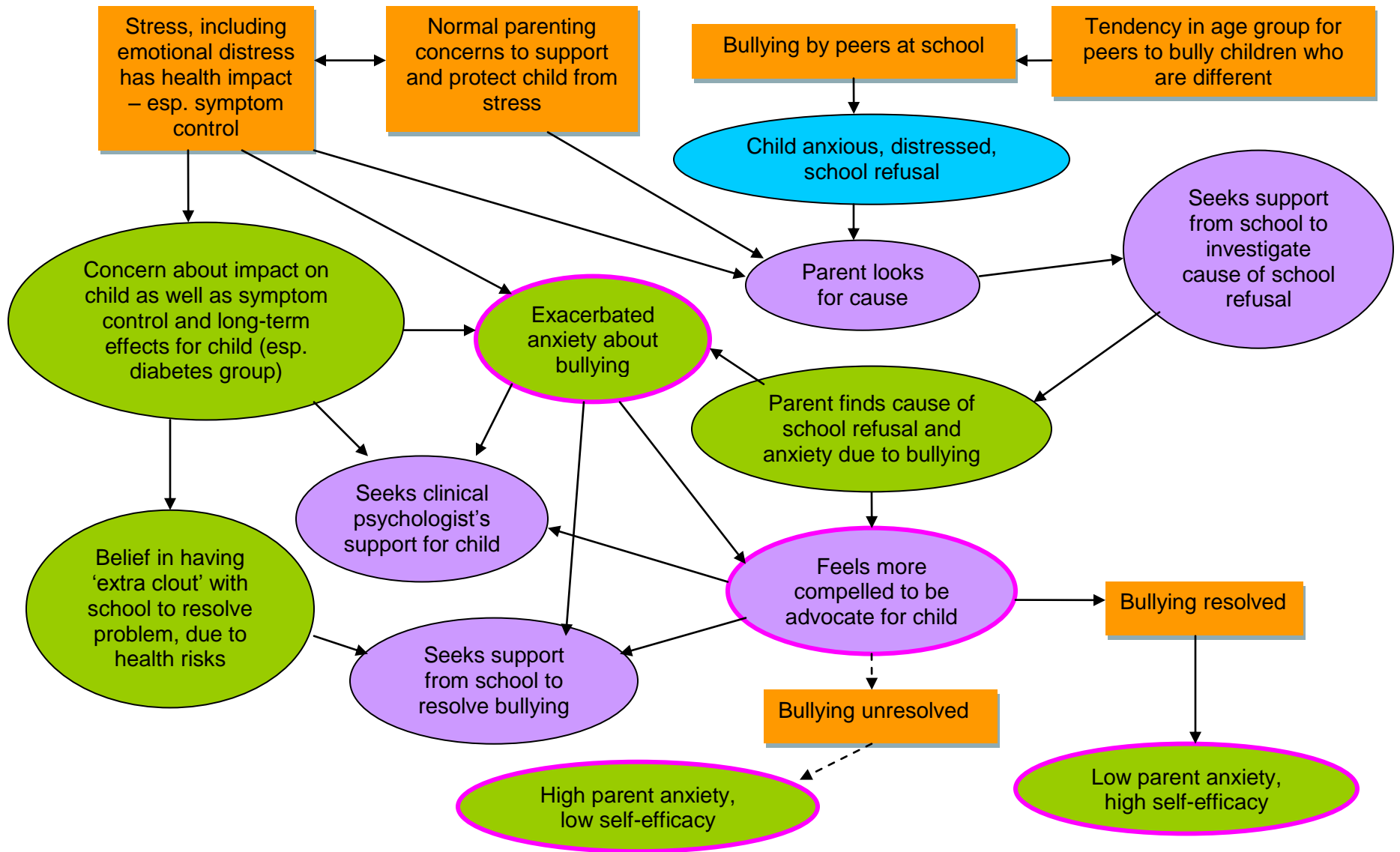
Appendix 7.17: Schematic Diagram 29: Extended family ethos of 'pulling together' and 'detachment' (both illness groups)



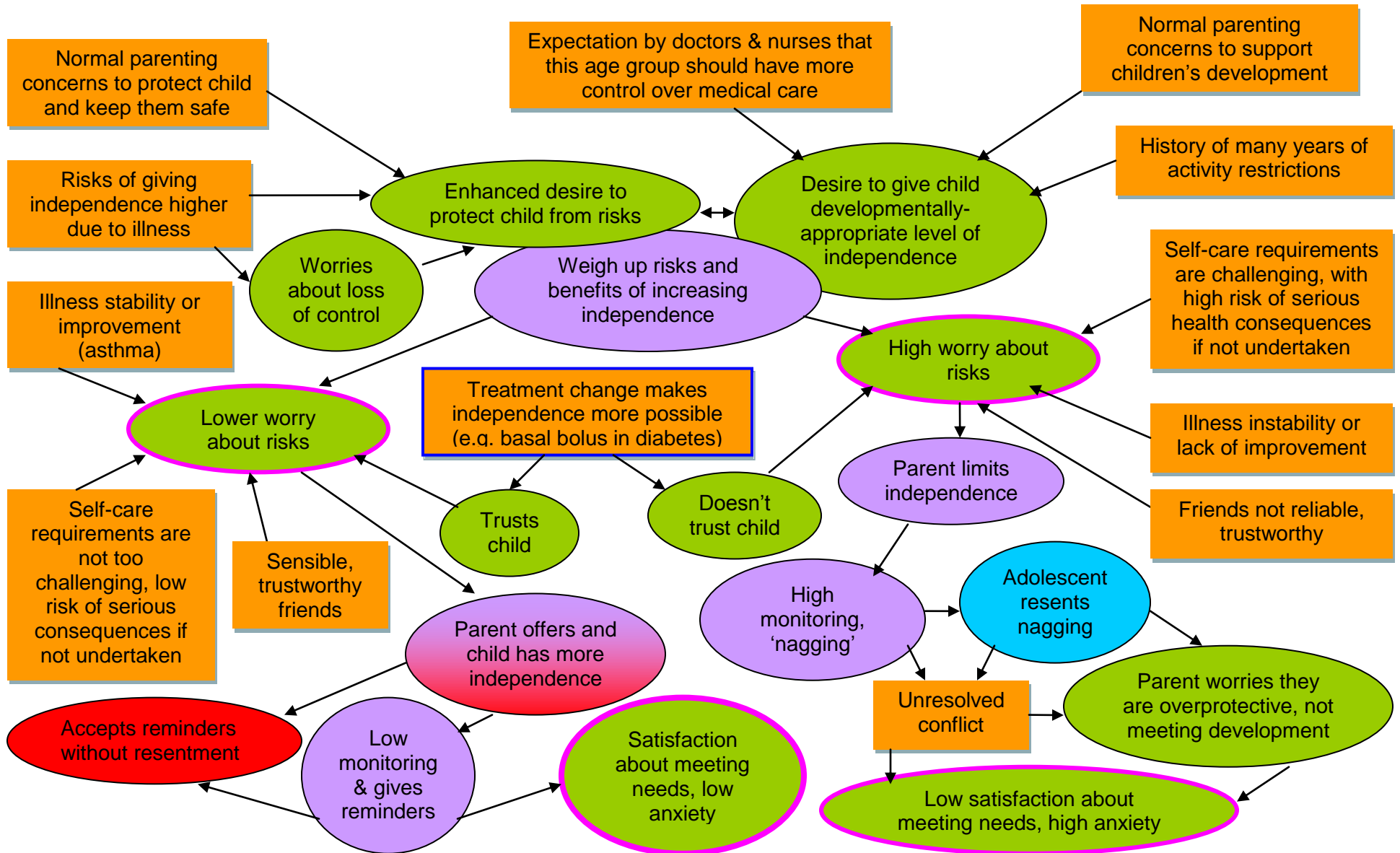
Appendix 7.18: Schematic Diagram 30: Added dimensions to parenting young children - (incorporating some findings from Chapter 4) (both illness groups)



Appendix 7.19: Schematic Diagram 31: Example of added dimension of parenting older children and adolescents – school refusal – diabetes group example, but applicable to both illness groups



Appendix 7.20: Schematic Diagram 32: Added dimension of parenting older children and adolescents - both illness groups



Appendix 8.1 Over-arching theme 1: The experience of parents' adjustment: Influences on stress, coping and efficacy
N.B.: Emboldened text means greater emphasis on this objective or theoretical proposition

Aspects of Over-arching Theme 1 (Table Title)	Chapters	Objectives	Schematic diagrams	Theoretical propositions	Key insights (incorporating those identified in the chapters)
Principles of parents' perspectives	4, 5, 6, 7	1, 2, 3, 4, 7, 8	1a, 1b, 2, 3, 4, 5	(i) , (ii) , (iii), (iv), (v), (vi), (vii), (viii), (ix), (x), (xi)(xiii), (xiv), (xv)	<ul style="list-style-type: none"> • Adjustment is dynamic not static, and varies with situations and time in the illness course. • Many person-specific (e.g. child age, temperament, parent's fears and coping abilities) and external factors (e.g. medication effectiveness) influence adjustment • Parents feel more positive about their life when they are able to effectively manage their child's illness, prevent or minimise health complications, perceive that treatment is not too great a burden, provide 'normal' experiences and developmental opportunities for the child's age, help the child to achieve their personal goals, be an effective parent, achieve their own life goals (within acceptable compromises), and when all family members' needs have been met. • Parents feel more negative about their life when their efforts to control the child's illness are not effective, where they are preoccupied with treatment, feel that the treatment burden is heavy, are overwhelmed with worry about the present and future for their child's health, development or life opportunities, feel unable to provide 'normal' experiences and opportunities for their child's goals and development, feel unable to influence their child's internalising, externalising or non-adherent behaviour, feel ineffective as a parent, have been unable to achieve personal life goals (or have made unacceptable compromises), and when all family members' needs have not been met.

Aspects of Over-arching Theme 1 (Table Title)	Chapters	Objectives	Schematic diagrams	Theoretical propositions	Key insights (incorporating those identified in the chapters)
Sources of stress impacting on coping	4, 5, 6, 7	1, 2, 3, 4, 7, 8	1a, 1b, 3, 4, 5, 6a, 13, 14, 15, 17, 19, 20, 23, 25, 26, 27, 31	(i), (ii), (iii), (iv), (v), (vi), (vii), (ix), (x), (xi), (xii), (xiii), (xiv), (xv)	<ul style="list-style-type: none"> • Negative relationships with doctors, not trusting • Anxiety about effect on siblings (e.g. witnessing distressing events) • Family ethos with excessive focus on the disease to the neglect of some family members • No knowledge or understanding of illness at time of diagnosis, or negative expectations (based on same illness in relatives). • Negative life experiences. • High perceived treatment burden. • Detached extended family ethos • Lack of shared care with partner • Siblings conflictual / disruptive behaviour • Times of transition (e.g. adolescence) when trust in child's competence / reliability is in question • Child's internalising or externalising behaviour, not accepting the illness • Child non-adherence to treatment • High numbers of different atypical episodes, where precursors or triggers not predicted. • Lack of improvement in child's health • Lack of opportunities for leisure, good social and working life, having to make unacceptable compromises in social or working life • Conflict between parenting objectives and health risks • Lack of control over outcomes (see factors detrimental to efficacy in box below)

Aspects of Over-arching Theme 1 (Table Title)	Chapters	Objectives	Schematic diagrams	Theoretical propositions	Key insights (incorporating those identified in the chapters)
Less effective coping strategies	4, 5, 6, 7	1, 2, 3, 4, 7, 8	1b, 11, 15, 19, 20, 23, 25, 27, 28	(i), (ii), (iii), (iv), (v), (vi), (vii), (x), (xi), (xii), (xiii), (xiv), (xv)	<ul style="list-style-type: none"> • Panics and avoids upsetting events (e.g. needle procedures) • Avoids or denies possibility of diagnosis, until symptoms impossible to ignore • Excessively vigilant with treatment monitoring and excessively preoccupied with minutiae of treatment ('Preoccupied' – diagram 25) • Overly protective of child with illness • Blaming child, self, doctors, teachers, siblings • Ambivalent response to child non-adherence, inconsistent responses to child misbehaviour • Excessively 'nagging' child about treatment, expressing anger at child, siblings, doctors • Tells self it is not possible to influence events / experiences • Excessive focus on child with illness, to detriment of other family members' needs
Factors detrimental to efficacy	4, 5, 6, 7	1, 2, 3, 4, 7, 8	1a, 1b, 3, 4, 10, 13, 15, 17, 19, 20, 30, 32	(i), (ii), (iii), (iv), (v), (vi), (vii), (viii), (ix), (x), (xi), (xii), (xiv), (xv)	<ul style="list-style-type: none"> • Limited coping support (where indicated in next box below) • Parents' own fears of needle procedures • Child not mature enough to understand, interpret and / or cope with some experiences • Child's excitable or argumentative temperament, or biological changes that make control difficult (diabetes) • 'Scatterbrained' child temperament, means forgets treatment (asthma) • Poor response to medication (asthma) or lack of hoped-for improvement in health • Atypical episodes, especially unpredicted and with poor outcomes • Repeated hospitalisations, or other adverse events despite parents' efforts • Child's condition apparently does not enable them to achieve strong goals (e.g. participating in active sports) • Child cannot participate in some 'normal' activities, which parent would like to offer • Parent belief that causes of child's externalising or internalising behaviour are not controllable or are due to parent actions • Lack of serious immediate consequences of some aspects of non-adherence • Unresolved conflict with adolescent over treatment

Aspects of Over-arching Theme 1 (Table Title)	Chapters	Objectives	Schematic diagrams	Theoretical propositions	Key insights (incorporating those identified in the chapters)
Sources of coping support	4, 5, 6, 7	1, 2, 3, 4, 7, 8	2, 4, 16, 20, 21, 23, 27, 28, 29, 30	(i), (ii), (vii), (ix), (xi), (xii), (xiii), (xv)	<ul style="list-style-type: none"> • Positive relationships with doctors, trusting • Teachers at school who are competent and reliable with regard to recognising symptoms and responding appropriately • Core family ethos of ‘pulling together’ (and extended family), although potential for some negative outcomes • Being able to experience negotiated, shared care e.g. with partner • Family expertise with illness experience and management (high heritability) • Child’s cooperative behaviour, child’s acceptance of the illness • Child’s supportive, reliable and knowledgeable friends • Supportive employers
Effective coping strategies	4, 5, 6, 7	1, 2, 3, 4, 7, 8	1a, 1b, 2, 16, 18, 20, 21, 22, 23, 24, 25, 28, 29, 30, 32	(i), (ii), (iii), (iv), (v), (vi), (vii), (x), (xi), (xii), (xiii), (xiv), (xv)	<ul style="list-style-type: none"> • Seeks social and medical support • Seeks information / looks for reasons for consequences of events • Positive reconstruction of negative experiences • Positive thinking (e.g. ‘it could be a worse illness’) / compares self with others with less good illness control • Thinks positively about child, trusts child (when trustworthy) • Accepts that can make mistakes, and tries to learn from mistakes • Reflects on own effective illness management strategies, and applies these in future • Reflects on own effective coping resources and mobilises them when anxious • Models adaptive behaviour to child (e.g. needle procedures) or otherwise provides effective support • Avoids stress of hospital readmission through extra treatment effort (asthma) • Accept reasonable risks, find a balance • ‘Operational’ approach to treatment management (diagram 25) • Undertaking social activities and leisure • Encourages family ‘pulling together’, but not neglecting each member’s needs

Aspects of Over-arching Theme 1 (Table Title)	Chapters	Objectives	Schematic diagrams	Theoretical propositions	Key insights (incorporating those identified in the chapters)
Factors promoting efficacy	4, 5, 6, 7	1, 2, 3, 4, 7, 8	2, 4, 10, 11, 12, 14, 16, 18, 21, 30, 32	(i), (ii), (iii), (iv), (v), (vi), (vii), (viii), (ix), (x), (xi), (xii), (xiv), (xv)	<ul style="list-style-type: none"> • (Coping support where indicated above) • Predictability of precursors (or triggers) of attack, relief of child's attack (having predicted or prevented it) • Consistent pattern of symptom presentation • Child's characteristics (likes routine, calm) (diabetes) • Identifies cause of internalising or externalising behaviour (symptoms or not) • Low perceived illness burden • Effective control follows treatment attendance and management advice • Child is mature enough to understand reasons for observed improvement in health, and continues to adhere to treatment • Child shows responsibility • Knowledge and skills to manage symptoms and illness in general (including those acquired from relatives) • Relatives with same illness have similar pattern of illness, and it is well controlled (asthma) • Better flexibility in lifestyle and illness management due to basal bolus system, provided child is responsible (diabetes)

Appendix 8.2: Over-arching theme 2: The significance of illness features that affect coping with the illness and with parenting tasks

N.B.: Emboldened text means greater emphasis on this objective or theoretical proposition

Aspect of Over-arching Theme 2 (Table Title)	Chapter	Objective	Schematic diagram	Theoretical proposition	Key insights (incorporating those identified in the chapters)
Illness features and illness experience	4, 5, 6, 7	1, 2, 3, 4, 7, 8	6a, 10, 11, 12, 14, 16, 17, 18, 19, 24	(i), (iii), (iv), (vi), (vii), (viii), (ix), (x), (xii), (xiii), (xiv), (xv)	<ul style="list-style-type: none"> • Heritability and match with relative’s experience / degree of severity – affects expectations, feelings and actions at diagnosis, support, knowledge, coping • Illness features of nature of onset, illness course and potential for the illness symptoms to improve or disappear – affects responses over time and feelings about the future • Age of diagnosis – affects efforts needed by parents to adapt (low level of child independence) and child’s acceptance of the illness • Degree of predictability / unpredictability of illness episodes or responses to treatment (see below) • Responsiveness to / effectiveness of medication (asthma) • Fearfulness of illness episodes and severity of consequences • Illness-specific dilemmas raised for parents that require challenging parenting decisions – finding a balance (see below)

Appendix 8.3: Over-arching theme 3: Assessing and balancing risks and benefits, deciding priorities

N.B.: Emboldened text means greater emphasis on this objective or theoretical proposition

Aspect of Over-arching Theme 3 (Table Title)	Chapter	Objective	Schematic Diagram	Theoretical proposition	Key insights (incorporating those identified in the chapters)
Making judgements	4, 5, 6, 7	1, 2, 3, 4, 7, 8	5, 9a, 9b, 13, 14, 15, 22, 24, 30, 32	(i), (ii), (iii) , (iv), (vi), (vii), (xii), (xiv)	<ul style="list-style-type: none"> • Parent weighs up risks and consequences of allowing risky activity versus promoting social development and independence • Are there known or unknown risks? • Does child have proven ability to manage independently? • Are there others who can care for child, and if so, are they trustworthy and competent? • Will it be too difficult for child to manage with the level of support? • Judges the consequences of failure – i.e. will it be severe?
Emotional consequences for parent of their decision	4, 5, 6, 7	1, 2, 3, 4, 7, 8	5, 9a, 9b, 13, 14, 15, 22, 24, 30, 32	(i), (ii), (iii) , (iv), (v), (x), (xii), (xiv)	<ul style="list-style-type: none"> • If emphasises protection, worries about loss of developmental benefits • If emphasises developmental benefits, worries about health risk • Evaluates severity of possible consequences of acting in either way – worries more if judges consequences of omission or action to be severe or very upsetting for child • Feels disappointment at restrictions