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The characteristics and experiences of anticipatory mourning in caregivers of teenagers and young adults: A systematic review

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Abstract

This article reports a systematic review of literature undertaken to identify characteristics and experiences of anticipatory mourning in caregivers of teenagers and young adults with life-limiting or life-threatening conditions. A comprehensive literature search was conducted using the keywords 'anticipatory', 'mourning', 'grief', and synonyms. This review focused on 6 studies that met inclusion criteria and reported characteristics of anticipatory mourning in caregivers of teenagers and young adults. Characteristics and experiences were sorted into four main themes: symptoms; a sense of loss; caregiver behaviour; and the unique experience of caring for, or losing, a teenager or young adult. The review suggests that there are characteristics and experiences of anticipatory mourning that are unique to caregivers of this age group. The review also suggests that consideration of anticipatory mourning is important in offering holistic care to young adults and their caregivers, *and* points to the need for further research in this area.

Introduction

There is a growing body of evidence about the experience of anticipatory mourning in caregivers. In a systematic literature review of grief in carers for people with dementia (Chan et al, 2012), anticipatory grieving was experienced as multiple losses, stress and anticipation about the future and was associated with caregiver depression. The process of anticipatory mourning in caregivers has been reported to cause symptoms, such as fatigue and exhaustion (Clukey, 2008), and a high proportion of parents of children with cancer were found to have severe anticipatory grief using the Marwit and Mueser Caregiver Inventory: Childhood Cancer scale that measures 'personal sacrifice burden', 'heartfelt sadness and longing' and 'worry and felt isolation' (Al-Gamal and Long, 2010). Clukey (2008) outlines the role of nurses in supporting caregivers experiencing anticipatory mourning, and a number of charitable and government organisations now publish information for caregivers to help them cope with grief before death.

Teenagers and young adults (TYAs) have only been considered as a distinct patient/client group with unique care needs in UK healthcare systems for the past 10 years (NICE, 2005); thus there is limited research about the needs, characteristics and experiences of *caregivers* for TYAs with life-limiting and life-shortening diseases. TYAs with life-limiting or life-threatening illnesses include TYAs diagnosed during childhood who may have outlived their life expectancy (Fraser et al, 2012), and those diagnosed during teenage and young adulthood. Our experience suggests that some caregivers of TYAs experience anticipatory mourning from diagnosis, which may be many years for this group of caregivers.

Professional input for caregivers who are experiencing anticipatory mourning can be positive and supportive in nature; unrecognised and unsupported anticipatory mourning may result in complicated mourning where the caregiver may become overwhelmed, resulting in crisis (Rando, 2000).

In 2005, the National Institute for Health and Care Excellence (NICE) reported that the specific needs of caregivers for TYAs with life-limiting or life-threatening illnesses have yet to be systematically explored. We conducted a systematic search and found no TYA-specific tools to assess anticipatory mourning in caregivers. Nor did we find primary research that specifically focused on assessing anticipatory mourning in

caregivers of TYAs. Therefore, we aimed to conduct a systematic review of data about anticipatory mourning extracted from primary studies that recruited (but weren't necessarily solely about) caregivers of TYAs with life-limiting and life-threatening illness.

Aims

This review aimed to identify characteristics and experiences of anticipatory mourning in caregivers for TYAs with life-limiting or life-threatening illnesses to enable health care professionals to be better informed when providing holistic care to this client group.

Background

The terms anticipatory mourning, anticipatory grief and forewarning of loss are much debated and interchangeable terms used to describe a unique phenomenon (Rando, 2000; Reynolds and Botha, 2006). The process of mourning may begin long before the death of a loved one and grief may be experienced even from the point of diagnosis (Lindeman, 1944; Parkes, 1986). Anticipatory mourning is most commonly experienced by family members and caregivers, but patients/clients and health professionals may also experience this phenomenon (National Cancer Institute, 2011).

Lindemann coined the term anticipatory grief in 1944 to describe grieving associated with a possible future death, as opposed to grief that followed a loss. Anticipatory grief is thought to be an initial reaction to the perception of loss, which is only one component of anticipatory mourning (Rando, 2000; Larson, 2000). The duration of grief, trajectory of emotional intensity, and scope of the experience differ between grief after death and 'anticipatory grief'. As opposed to grief after death, anticipatory grief may begin at diagnosis, ends at death and the emotional intensity of anticipatory grief increases over time (Costello, 1999). The

definition of anticipatory mourning that includes anticipatory grief, coping, adjustment to the loss, and psychosocial re-organisation (Larson, 2000; Rando, 2000) was used in this study.

The age range that describes teenagers and young adults varies across international literature from 15 to 39 years old (Bleyer et al, 2006; CRUK, 2014), but teenagers and young adults most commonly refers to young people aged 16 to 25 years old. One reason this review was conducted was to inform practice in a hospice setting that cares for young people aged 16 to 35. However, the age inclusion criteria used in this study was caregivers of 16-25 year olds, to ensure consistency with commonly used age ranges for teenagers and young adults. The study focuses on the experience of *caregivers* of 16-25 year olds, and not that of patients/clients, or health professionals. For the purpose of this review we use the term caregiver to describe the individual primary provider of care to the TYA with a life-limiting or life-threatening illness, predominantly parents.

Method

Search strategy

The keywords 'grief', 'anticipatory AND grief', 'mourning', 'anticipatory AND mourning' were used to search 'all terms' in the MEDLINE, PubMed, CINAHL, BNI, AMED and PsycInfo databases. The search was expanded by searching catalogues of two libraries, Google books and snowballing reference lists of relevant literature. The authors restricted the publication language to English and no date limitation was used.

Inclusion and exclusion criteria

To capture the breadth of research reporting anticipatory grief or mourning in caregivers of TYAs with life-limiting or life-threatening illnesses, all types of articles that reported relevant primary data were included

in the review. All other types of articles, i.e. those where data about caregivers of TYAs could not be extracted for review, or were not primary research, were excluded.

Appraisal and exclusion process

All citations were reviewed by RG. Citations of potentially relevant titles that did not include an abstract were obtained in full text. A sample of every third citation was independently reviewed for exclusion decision by VL. All citations that had possibly relevant content were retrieved in full text to assess for inclusion. Exclusion of articles retrieved in full text were discussed and agreed by the researchers.

The quality of reviewed articles was assessed using the relevant critical appraisal skills programme tool (CASP, 2010). Quality assessment and exclusion decisions of full text articles were conducted by two independent researchers (RG and KD). Based on the CASP quality assessment criteria articles were assessed as either being low, moderate, or high quality; only moderate- and high-quality studies were reviewed. The exclusion process is summarised using a PRISMA flow-diagram (Figure 1).

The data extraction criteria used are shown in Table 1. Reported data about the characteristics and experiences of caregivers in relation to anticipatory mourning were coded as: loss of a TYA; loss of family; loss of normality; being protective; fear for the future; experience of parent caring for the TYA; financial worries and pressure; anxiety; uncertainty; despair; isolation; relief; physical symptoms of the caregiver; need to be in contact with others in similar situations; guilt and self-blame; suicidal ideation; placing child before self; and spiritual concerns(s) (Figure 2).

Secondary data were further analysed using thematic analysis. The coded main findings were sorted using a mind map to identify emergent themes (Figure 2). Themes that emerged from the mind mapping exercise were: symptoms; a sense of loss; caregiver behaviour; and the unique experience of caring for, or losing, a teenager or young adult (Figure 2). A narrative of the researchers' interpretation of main findings

in relation to characteristics and experiences of anticipatory mourning in this caregiver population is presented in the results section.

Results

580 sources were retrieved, 128 abstracts were screened, and 38 full text articles were assessed for relevance. Of those, 32 were critically appraised. Of those, six articles were reviewed to identify characteristics and experiences of anticipatory mourning in caregivers of TYAs with life-limiting or life-threatening illnesses (Table 1). Articles were excluded if they did not report extractable data relating specifically to caregivers of TYAs aged 16 - 25 (Figure 1).

Countries of origin were the United Kingdom (Grinyer and Thomas, 2001; Grinyer, 2002; Grinyer, 2012; Price et al, 2011) and the United States of America (Peteet et al; Sobel and Cowen, 2003).

All studies included in the review were methodologically robust qualitative research, which included an interpretive qualitative approach with semi-structured in-depth interview (Price et al, 2011); a narrative, semi-structured interview (Sobel and Cowen, 2003); narrative correspondence (Grinyer and Thomas, 2001; Grinyer, 2002); a mixed method grounded theory study (Grinyer, 2012); and a case study (Peteet et al, 2010).

Four articles reported narratives from recently bereaved parents of TYAs with cancer or other life-limiting illness (Grinyer and Thomas, 2001; Grinyer, 2002; Grinyer, 2012; Price et al, 2011). One contained narratives from five parents that were caring for their TYA children (Grinyer and Thomas, 2001). One reported the experience of family members who have completed genetic testing for life-limiting illness (Sobel and Cowen, 2003). Another reported the wishes of a mother whose twenty-one year old daughter was dying in intensive care (Peteet et al, 2010).

Theme 1: Symptoms of anticipatory mourning in caregivers of TYAs

Psychological, social, and physical symptoms of anticipatory mourning were described in five studies. Psychological symptoms included fear for the future, anxiety, uncertainty, despair, relief and spiritual concerns (Grinyer, 2002; Grinyer, 2012). Caregivers also experienced guilt (Grinyer, 2002; Sobel and Cowen, 2003) and self-blame about genetic predisposition to the diagnosis (Sobel and Cowan, 2003). Social symptoms described commonly included isolation (Grinyer 2002; Grinyer 2012), as well as financial worries and pressure (Grinyer and Thomas, 2001). Isolation might be reduced by meeting others in similar situations (Grinyer, 2002). Physical symptoms included: deterioration in the carer's physical health, insomnia, disrupted digestion, shallow breathing, palpitations, sweating, a physical sensation of having a huge lump in the chest all the time, stress, and becoming increasingly unwell (Grinyer, 2002).

Theme 2: Sense of loss

A sense of loss was described in three studies (Grinyer and Thomas 2001; Grinyer 2002; Grinyer 2012). These described loss of their child's independence as their disease progressed (the TYA having previously grown into independence through ageing); loss of the normality of life prior to diagnosis; and loss of ability to protect and make decisions for and on behalf of their child. Caregivers also expressed loss about a perceived future based on how their family was prior to diagnosis (Grinyer and Thomas, 2001; Grinyer, 2002; Grinyer, 2012). Grinyer (2012) reported one participant describing their family as 'broken'.

Theme 3: Behaviours related to anticipatory mourning

Behaviours related to anticipatory mourning are reported in all the reviewed studies. These behaviours include being protective (Price et al, 2011; Grinyer, 2012), placing the TYA (their child or partner) before themselves (Grinyer, 2002), and planning suicide (Peteet et al, 2010). Fear of the TYA choosing to stop

treatment was also expressed; one participant adamantly did not want her child to know they were dying (Grinyer and Thomas, 2001).

Theme 4: Unique experience of caring for, and losing, TYAs

Parents reported that they became caregivers of their 'adult' children (Grinyer and Thomas, 2001; Grinyer, 2002; Grinyer, 2012; Price et al, 2011). They described being thrown back into an 'outgrown' family experience and families being under a major strain (Grinyer and Thomas, 2001). Caregivers reported being providers of personal care and age-specific emotional support that as parents they would not usually undertake, relating to lack of sexual experiences, fertility, and specifically how to prepare for death (Grinyer and Thomas, 2001; Grinyer, 2012). Caregivers referred to the TYA they were caring for as 'half child – half adult' (Grinyer, 2012). They also found communication about death and dying with professionals and the TYA difficult and complex, as they or the TYA might not have wanted to talk openly about end of life (Grinyer and Thomas, 2001; Grinyer, 2002; Grinyer, 2012). Caregivers described their friends as having no perception of their situation, or need for practical support, which was due to the TYA not being a child, but an adult (Grinyer, 2001). Some parents were reported as having difficulty in accepting that their sick child was an adult (Grinyer, 2002).

Discussion

This review found few published studies on the topic, and no research that specifically examined the characteristics and experiences of anticipatory mourning in caregivers of TYAs with life-limiting or life-shortening conditions. However, this review suggests that anticipatory mourning is experienced in this caregiver group, which correlates with our experience in practice and demonstrates a need for an awareness of the phenomenon. Synthesises of evidence reported in this review suggests that those

working in the field of teenage and young adult palliative care should stop and think about the experiences of caregivers in light of anticipatory mourning.

It is recognised that symptoms described could also have other causes, such as caregivers' baseline physical health, stress, depression, anxiety, poor nutrition, sleep deprivation or the use of drugs, caffeine or alcohol (Hearson et al, 2011; Rando, 2000; NHS, 2012; NHS, 2010). However, these symptoms might also be part of anticipatory mourning (Corr and Corr, 2000) and caution, therefore, must be taken to assess and treat these symptoms in a holistic way. Key times to conduct possible symptoms of anticipatory mourning might include the point of diagnosis where loss of the TYA is considered a risk, at times when the TYA experiences loss of a skill increasing their dependence on a caregiver, or as end of life seems near.

The experience of symptoms might be dependent on the individual's perception, evaluation and response to them (Dodd et al, 2001a). Where there are three or more concurrent symptoms, an examination of symptom clusters might be useful (Dodd et al, 2001b). This might indicate ill health, overwhelming anticipatory mourning, and/or a reduced quality of life in the carer. Symptom clusters might cause adverse effects and this might be a point at which specific interventions should be considered (Dodd et al, 2001b). In practice, Rando's (2000) recommendation that professionals should focus on the issues that are *distressing the carer*, seems appropriate for caregivers of TYAs.

The psychological and social symptoms found in these caregivers might also relate to the parts of anticipatory mourning that Rando (2000) describes as 'psychosocial reorganising'. This is where the carer is recognising and continually coming to terms with diagnosis and losses, what these means to them, their loved one and their circumstances. O'Brien et al (2012) recommend that caregivers of adults with terminal illnesses receive counselling, specifically discussing how things are now and their fears about how to cope in the future. Practice suggests that some caregivers of TYA need pre-bereavement support, which might

be counselling, in the context of TYA care. TYA-specific family support services might be of value; however no evidence evaluating counselling interventions was found in this review.

Chapman and Pepler (1998, p227) describe a 'paradox of how to maintain hope while facing the reality that a loved one is dying'. They discuss supporting caregivers to manage this balance (between facing losses and maintaining hope), with the goal of enhancing a family's growth to continue caring in the face of terminal illness, as a constructive action in an otherwise negative situation. Maintaining hope at varying levels was evident within the reported experiences of loss of caregivers, often within the context of the caregiver wishing to withhold information from the TYA about their prognosis in an effort to protect them.

Studies suggest that caregivers find meaning through caring or 'doing' in adult and child studies, where the caregiver puts the cared-for before themselves (Duke, 1998; Sutherland, 2009; Price et al, 2011). However, placing the patient's needs and wants before their own can make both the carer and the patient more vulnerable, as the stress of caring might create a greater burden over time (Salinger and Cain, 2004; Hearson et al, 2011). With increasing numbers of children with life-limiting conditions living into adulthood this issue is perhaps of particular relevance to caregivers of TYAs. Whilst behaviours might be understood as part of anticipatory mourning, extremes of behaviours (such as suicidal ideation) could be an indicator of not dealing with or managing anticipatory mourning.

This review has highlighted unique aspects of caring for and losing TYAs. Caregivers of TYAs have a sense of carer responsibility (often as parents) to provide care, but some feel excluded because the young person has legal autonomy in decision making. In child and adult studies, Decruyenaere et al (2005) and Al-Gamal and Long (2010) recommend greater family involvement around the point of diagnosis, to enable good communication within these families and prevent crisis. Parents value respite and support that provides individualised, holistic, family-centred care, which promotes control and active involvement in decision making (Kirk and Pritchard, 2011; Whiting, 2014). However, such involvement is dependent on permission

of the adult TYA. In the UK, in order to maintain confidentiality, permissions for direct contact with a parent or carer are needed from the TYA, if they are 18 or over and have mental capacity (NMC, 2008; Mental Capacity Act, 2005). As a consequence, the carer might feel a sense of isolation in their experience, and might feel excluded from decision making that affects them directly.

Social isolation is described in anticipatory mourning where one 'may withdraw emotionally and/or physically from social contacts and responsibilities due to the grief or mourning' (Chapman and Pepler, 1998). Parents in Grinyer (2002) found sharing with others in similar situations gave comfort, and perhaps opportunity to share their perceived unique experience. Carer to carer contact might be facilitated, where wished for, in the format of family support groups, electronic protected message-boards, social media groups and family conferences. However, evidence of research into effectiveness of any of these interventions could not be found in this review.

Limitations

Data reviewed was restricted to studies that were published in English. Studies that did not publish details of the participants' age, or in which data was published about TYA caregivers that could not be independently extracted, were excluded from the review. The sample group was self-selected for all studies, which might have introduced bias. Owing to the limited work conducted in this field, this review relies heavily on the work of one author (Grinyer). Data that could be extracted from publications by other authors presented data on six cases in total; these, when combined with data reported by Grinyer, added credibility and depth to the data set as a whole. A key challenge in interpreting findings was that baseline data of characteristics of caregivers were not recorded. Thus, reported symptoms and behaviours in caregivers could be attributed to factors other than being a caregiver of a TYA with a life-limiting or life-threatening illness. There was also variation in participants; for example some were still acting as caregivers and others were bereaved, which may have confounded the findings of this review.

Characteristics and experiences of anticipatory mourning were defined, coded and sorted into themes by the research team using inductive reasoning, so analysis and synthesis of the data retrieved is open to challenge.

Conclusions

This review indicates that there are particular and notable characteristics and experiences of anticipatory mourning seen amongst caregivers of TYAs. These are psychological, social and physical symptoms, a sense of loss, particular behaviours associated with anticipatory mourning, and the unique experience of preparing to lose a TYA to a life limiting or life shortening condition.

This review indicates that further research is needed into the TYA caregiver experience of anticipatory mourning. This study found limited relevant material, but the available evidence suggests that the characteristics and experiences of caregivers of TYAs with life-limiting and life-threatening illness might differ from other caregivers. To enable fuller comparisons future research needs to include baseline information, in particular the age of the person being cared for.

In terms of practice, this review has explored anticipatory mourning in this specific group of caregivers. In order to provide holistic care, healthcare professionals supporting TYAs in palliative care should consider whether caregivers are experiencing anticipatory mourning and, if they are, ensure that appropriate support is in place.

With further experiential evidence, it might then be possible to compare TYA caregivers' experiences to those of caregivers of children or older adults, in order to adapt current tools of assessment. The aim would be to develop and examine assessment criteria to enable equitable support and useful/appropriate interventions for this group. Current support and interventions need to be examined, in light of benefits to both TYAs and their caregivers. Future research may inform the development of outcome indicators for the management of anticipatory mourning in caregivers.

Better understanding of anticipatory mourning in this group should enable practitioners to offer a more responsive, individualised and holistic approach to TYA caregiver support in palliative care. Support and interventions should be sought that aim to improve caregivers' psychological, social and physical health and wellbeing, in a way that is sensitive to the complexity of their specific needs.

Key Words

Anticipatory mourning

Anticipatory grief

Caregivers

Carers

Teenagers and young adults

Systematic review

Reference list

Al-Gamal E, Long T (2010) Anticipatory grieving among parents living with a child with cancer. *J Adv Nurs* 66:9 1980-90

Bleyer A, Budd T, Montello M (2006) Adolescents and Young Adults with Cancer: The scope of the problem and criticality of clinical trials *Cancer* 107:7 1645-55

CASP (2010) *Critical appraisal skill programme – making sense of evidence about clinical effectiveness.*

Qualitative research checklist [online] Retrieved 2/2/2015 at
media.wix.com/ugd/dded87_951541699e9edc71ce66c9bac4734c69.pdf

Chapman K, Pepler C (1998) Coping, hope, and anticipatory grief in family members in palliative home care. *Cancer Nurs* 21:4 226-234

Chan D, Livingston G, Jones L, Sampson E L (2012) Grief reactions in dementia carers: A systematic review
Int J Geriatr Psychiatry 28 1-17

Clukey L (2008) Anticipatory mourning: processes of expected loss in palliative care *Int J Palliat Nurs* 14:7
316-325

Corr CA , Corr DM (2000) Anticipatory mourning and coping with dying; similarities, differences, and suggested guidelines for helpers. In: Rando T (ed) *Clinical Dimensions of Anticipatory Mourning*, Research Press, Champaign, Illinois, USA: 233-51.

Costello J (1999) Anticipatory grief: coping with the impending death of a partner. *Int J Palliat Nurs* 5:5
223-31

Cancer Research UK (2014) Teenage and young adult cancer: Cancer statistics. Key facts [online] Retrieved 2/2/15 at publications.cancerresearchuk.org/downloads/Product/CS_KF_TYA.pdf

Decruyenaere M, Evers-Kiebooms G, Boogaerts A, Demyttenaere K, Dom R, Fryns J-P (2005) Partners of mutation-carriers for Huntington's disease: forgotten persons? *Eur J Of Human Genetics* 13:9 1077-85

Dodd H, Janson S, Facione N, Faucett J, Froelicher E, Humphreys J, Lee K, Miaskowski C, Puntillo K, Rankin S, Taylor D (2001) Advancing the science of symptom management. *J Adv Nurs* 33:5 668-76

Dodd M, Miaskowski C, Paul S (2001) Symptom clusters and their effect on the functional status of patients with cancer. *Onc Nurs Forum* 28:3 465-70

Duke, S (1998) An exploration of anticipatory grief: the lived experience of people during their spouses' terminal illness and in bereavement *Jour Adv Nurs* 28:4 829-39

European Association of Palliative Care (2007) Taskforce: IMPaCCT: Standards for paediatric palliative care in Europe *European Journal of Palliative Care* 14: 2-7

Fraser L, Miller M, Hain R, Norman P, Aldridge J, McKinney P, Parslow R (2012) Rising National Prevalence of Life-Limiting Conditions in Children in England *Pediatrics* 129:4 923-4

Grinyer A, Thomas C (2001) Young adults with cancer: the effect on parents and families *International Journal of Palliative Medicine* 7:4 162-70

Grinyer A (2002) *Cancer in Young Adults. Through Parents Eyes* Open University Press, Milton Keynes

Grinyer A (2007) The biographical impact of teenage and adolescent cancer *Chronic Illness* 3:4 265-77

Grinyer A (2012) *Palliative and End of Life Care for Children and Young People: Home, Hospice ... and hospital*. Wiley-Blackwell, Oxford

Hearson B, McClement S, Mcmillan DE, Harlos M (2011) Sleeping with One Eye Open: The sleep experience of family members providing palliative care at home *J Palliat Care* 27:2 69-78

Hultman T, Keene Reder E, Dahlin C (2008) Improving psychological and psychiatric aspects of palliative care: The National Consensus Project and the National Quality Forum Preferred Practices for Palliative and Hospice Care *Omega: J Death & Dying* 57:4 323-39

Kirk S, Pritchard E (2011) An exploration of parents' and young people's perspectives of hospice support
Child Care Health Dev 38:1 32-40

Larson D (2000) Anticipatory mourning: Challenges for professional and volunteer caregivers. In: Rando T A, ed *Clinical dimensions of anticipatory mourning: Theory and practice in working with the dying, their loved ones and caregivers* Research Press, Champaign, Illinois, US: 379-95

Lindemann E (1944) Symptomatology and management of acute grief. *Am J Psychiatry* 101: 141 -148

The Mental Capacity Act (2005) HMSO, London

National Cancer Institute (2011) *Anticipatory Grief. Health Professional version, Grief, Bereavement and coping with loss* [online] Retrieved 6/2/2012 at
www.cancer.gov/cancertopics/pdq/supportivecare/bereavement/HealthProfessional/page3

NHS (2010) *Depression symptoms, Anxiety symptoms* [online] Retrieved 16/10/12 at
www.nhs.uk/Conditions/Depression/Pages/Symptoms.aspx?WT.mc_id=51109

NHS (2012) *Stress symptoms* [online] Retrieved 17/10/12 at
www.nhs.uk/Conditions/Stress/Pages/Symptoms.aspx

NICE (2004) *Improving supportive and palliative care for adults with cancer*. Cancer service guidance, CSGSP
[online] Retrieved 2/3/2012 at www.nice.org.uk/CSGSP

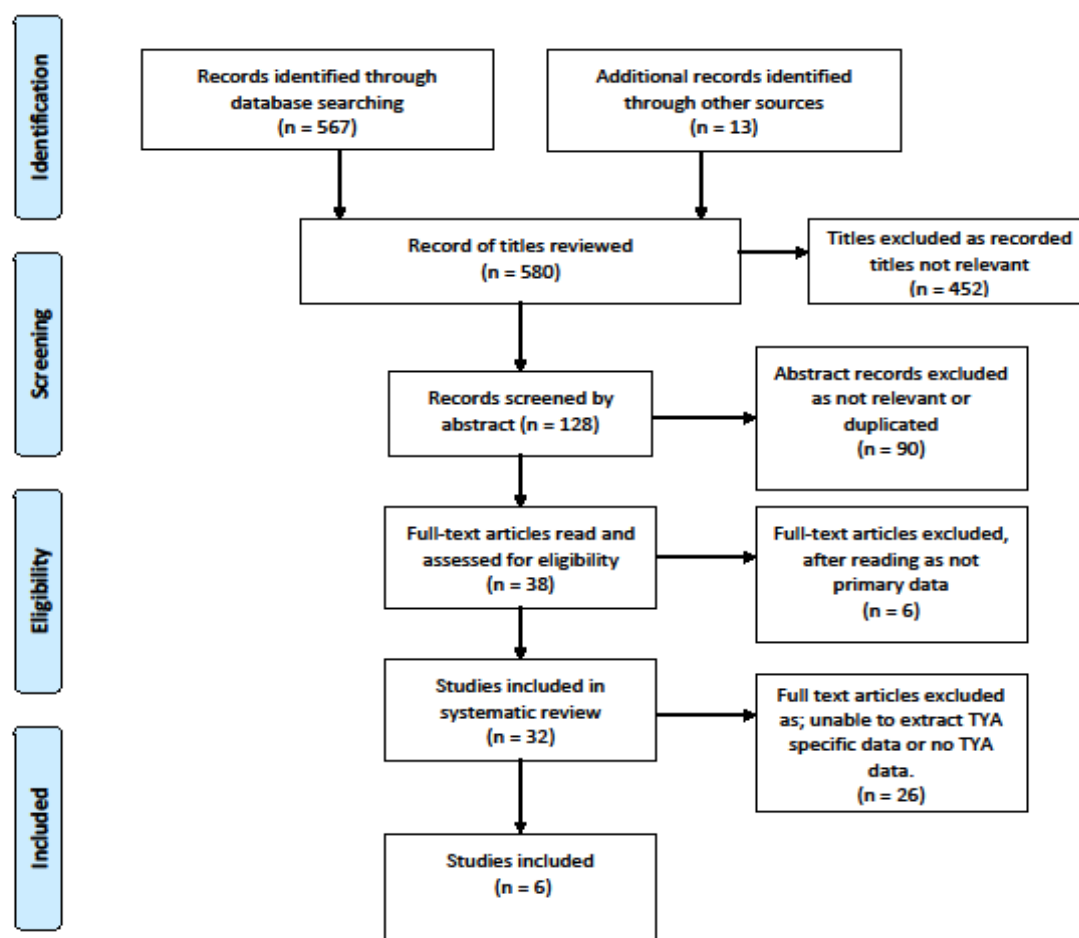
NICE (2005) *Improving outcomes in children and young people with cancer. The Manual*. [online] Retrieved 29/5/2015 at www.nice.org.uk/guidance/csgcyp/evidence/improving-outcomes-in-children-and-young-people-with-cancer-manual-update-2

- O' Brien M, Whitehead B, Jack BA, Mitchell JD (2012) The need for support services for family carers of people with motor neurone disease (MND): views of current and former family caregivers a qualitative study. *Disabil Rehabil* 34:3 247-56
- Parkes CM (2010) *Bereavement. Studies of Grief in Adult Life*, 4th edn. Penguin, London
- Peteet J, Maytal G, Rokni H (2010) Unimaginable loss: Contingent suicidal ideation in family members of oncology patients *Psychosomatics: J of Consultation Liaison Psychiatry* 51:2 166-70
- Price J, Jordan J, Parkes J (2011) Living through the death of a child: a qualitative study of bereaved parents' experiences *Int J Nurs Stud* 48:11 1384-92
- Rando TA, ed (2000) *Clinical Dimensions of Anticipatory Mourning: Theory and practice in working with the dying, their loved ones, and caregivers*. Research Press, Champaign, Illinois, US
- Reynolds L, Botha D (2006) Anticipatory grief: Its nature, impact and reasons for contradictory findings *Counselling, Psychotherapy and Health* 2:2 15-26
- Saldinger A, Cain AC (2004) Deromanticizing anticipated death: denial, disbelief and disconnection in bereaved spouses *J Psychosocial Oncology* 22:3 69-92
- Shama W, Lucchetta S (2007) Psychosocial issues of the adolescent cancer patient and the development of the Teenage Outreach Program (TOP) *J Psychosocial Oncology* 25:3 99-112
- Sobel S, Cowan C (2003) Ambiguous loss and disenfranchised grief: the impact of DNA predictive testing on the family as a system *Family Process* 42:1 47-57
- Sutherland N (2009) The meaning of being in transition to end-of-life care for female partners of spouses with cancer *Palliative & Supportive Care* 7:4 423-33

Whiting M (2013) Impact, meaning and need for help and support: The experience of parents caring for children with disabilities, life-limiting/life-threatening illness or technology dependence *Journal of Child Health Care* 17:1 92–107



Figure 1. PRISMA 2009 Flow Diagram
Adapted from Moher et al (2009)



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* 5(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.

PRISMA flow-diagram showing exclusion process within this systematic review

Table 1.

Author	Title and country of origin	Study type, sample and quality rating	Themes Category coded by letter	Examples of coded data by category
Grinyer and Thomas (2001)	Young adults with cancer: the effect on parents and families (U.K.)	Qualitative study (prospective and retrospective) 22 parental accounts, 17 of whom TYAs had died Self-written sample TYAs 18 -25 years old Quality rating: High with limitations	Sense of Loss: Grief or mourning expressed when losses experienced	
			A. Loss of TYA	"That was the last time we saw him alive... "Helen p166
			B. Loss of family	"I remember very clearly the terrible pain I felt having to leave either [the TYA or sibling] when I knew how much they both needed me." Candy p169
			C. Loss of independence of the TYA	"Alexander was altogether weak and helpless and financially dependent on us again." p166
			D. Loss of normality	"We had not lived together for the previous 1 ½ year, now we were thrown back into a family situation we had outgrown." Sue p166
			Behaviours demonstrated by caregivers in relation to the TYAs condition	
			E. Being protective	"I was adamant that I did not want my son to know he was dying. As he was an adult this was a constant battle." Brenda p168
			Unique experiences of caring for and losing these TYA Challenges generated by tension between dependence due to TYAs condition and the TYAs need for independence because of the life stage of young adulthood.	
			G. Unique experience of caring for and losing these TYA	"Because we no longer had very small children... but adults, people around us either did not perceive any particular need to offer practical help... or did not know how to help " Sue p168
			Symptoms These include psychological, social, physical and spiritual symptoms that could be attributed to anticipatory mourning.	
			H. Financial worries	"Most young people will still be financially dependent on their parents, who may be struggling to meet mortgage repayments and support their other siblings in further education, training or school. This may well be the most challenging time financially and cause more problems than with younger children. Yet we discovered that we were not eligible for much help, nor was the situation perceived to be possibly problematic. Whilst younger children are often (and rightly) on the receiving end of charity handouts, the spotty, rebellious teenager misses out!" Sue p 169
			K. Despair	"You are in despair...Tell me how to handle this mum? I don't know how to die". You cried and screamed and we held you. We didn't know what to tell you to feel. Only be there with you." Stephanie mother of Paul P167

Grinyer (2002)	Cancer in Young adults – through parents eyes (U.K.)	<p>Qualitative (prospective and retrospective)</p> <p>Self selected sample 27 accounts written by parents</p> <p>Method of analysis cross-sectional in the search for common themes. Narrative view/ ethical integrity and practical relevance/social science method</p> <p>TYAs 15 – 26 with cancer (data on 15 year olds and 26 years olds excluded from this review)</p> <p>Quality rating: High with limitations</p>	Sense of Loss	
			A. Loss of TYA	“Sara [aged 25] asked in a quiet voice, Mum am I going to die?’ I replied ‘No you’re not’ in a voice that tried to convince us both, but deep down I think we both knew.” Carol p146
			B. Loss of family	“Most of his treatment was in the Hammersmith hospital in London, a good 3 hour journey from our home. We travelled to and from the hospital several times a week often together, too often alone. One parent with Chris, the other at home trying to keep life normal for our 11 year old” [mum to Chris who died age 20] Anne p106
			D. Loss of normality	“Sit down mum. Listen to me. No more talk of independence, I have not got long now. I want to come and live with you and Richard, make it my home again, I want you to give up work and look after me until I die” [mum to Steve age 24] Gabrielle p29
			Behaviours	
			E. Being protective	“I couldn’t tell her how she had always been my life, my window on the world, talk about what a wonderful child she had been, for fear of touching the raw nerve underneath; I didn’t want her to hear my voice falter or see my tears.” [TYA Nicola died aged 22] Mary p153
			Q. Suicidal ideation	“The seriousness of the situation we all found ourselves in was so frightful I almost hoped we would be wiped out on the M3 by some wanker in a BMW - at least I would not have the wild thoughts and macabre images already mapped out in my mind as Simon’s existence [aged 21] for the next 12 weeks.” Lynn p151
			R. Placing TYA before self	“ Sean’s needs [age 20] and welfare were more important than my loss” Charlotte p155
			Unique experience of caring for and losing these TYA	
			G. Experience of caregiver caring for and losing these TYA	“Sometimes Alex [aged 20] was back to being the child again, expecting us to sort out all the unpopular tasks, such as insurance and registrations, or clamouring for an ice cream, wanting a cuddle and a kiss and generally basking in family love. But at other times – in keeping with his age and circumstances – he was the young adult who could manage perfectly well without interfering parents, thank

			you very much! We also kept forgetting which role we were playing or supposed to play... a muddle. (Sue p27)
		G. Experience of caregiver caring for and losing these TYA	"No—one understands this. They can't. A friend who lost her husband when he was 52 tries to compare this- Jim had a lot of life left to live. BUT HE <u>HAD</u> A LIFE – ALASTAIR DIDN'T GET A CHANCE. She <u>doesn't</u> understand she didn't watch her child suffer agony and be helpless to do anything about it." Moira Mother of Alastair age 19 p143
		O. Need to be in contact with similar others	"I think it did help to meet another mother in a similar situation, I didn't feel so isolated, so unusual. So alone." Carol Mother of Sara who died aged 25 p145
		Symptoms	
		F. Fear for the future	"And as soon as those metastases were found on the x-rays I 'knew ' that he couldn't survive, so all of the uncertainty of the previous three years, the hope and the fear and the check-ups, the possibility of a future and the possibility of death all suddenly evaporated." Helen Mother of George who died aged 24 p141
		I. Anxiety And J. Uncertainty	"Really for me there were two distinct situations; one was the emotional impact of George's illness and dying which I have to separate out from the emotional impact of bereavement. So first of all when I remember the emotional impact of the four years of his illness it was a most physical experience. I can't really remember the anxiety, the uncertainty and the despair without remembering all the physical symptoms..." Helen p140
		K. Despair	"Watching the 'Good Morning' programme.....Who the hell gives a damn as to what to buy your best friend for Christmas, do I care about the price of Brussel sprouts, for God's sake don't you all know, can't you see that I am suffering here, I am dying inside. My son is dying....What's wrong with this world? You have no right to be happy." Barbara Mother of Jamie diagnosed aged 18 p150
		L. Isolation	"I think, I felt quite isolated, at that time though (time of diagnosed metastases), because until the last six month of his life Geoff and Jonathon and most of the people close to us still seemed to be of the belief that George could be cured. But I felt certain that he couldn't." Helen p141

			M. Relief	““The fact that he died at home and peacefully was for me I suppose a huge achievement. So at the point of bereavement there was enormous relief.” Helen p141
			N. Physical symptoms	“remembering all the physical symptoms of insomnia, of disrupted digestion of shallow breathing, of palpitations, of sweating, of having a huge lump in my chest all the time, that was how it affected me – at a very, very physical level.” Helen p140
			S. Spiritual concerns	“When we realised death was near, it seemed natural to talk about what would happen after, though we had never spoken about spiritual things before.....I hope he [Simon aged 19] was able to talk to the nurses in the hospice about dying. I wish I could have done more of this. I’ve lost any attachment to organised religion myself... not all that pleased with God either.” Helen V p159
			P. Guilt – self blame	“I am still fighting with the belief that it is all my fault as I must have done/not done something during his short life to cause his nightmare.” Lynn Mother of Simon R who died aged 21 p 151
Grinyer (2012)	Palliative and End of Life Care for Children and Young People: Home, Hospice and Hospital (U.K., U.S.A)	Qualitative (retrospective) Self selected sample Interviews: first-hand accounts of what it is like to care for children who have LLC 43 participants:21 professionals (hospice staff); 22 parent interviews (bereaved parent, siblings and	Sense of Loss	
			B. Loss of family	“I don’t think that he [surviving son Jed] liked the way that it was.. he didn’t like the family being broken.....and everyone was all battling against each other because we was all.. you know...With Joe’s illness...I dealt with it one way, Gary dealt with it another way and we was all battling against each other and he didn’t know... he didn’t like that.” Clare Mother of Ben who died aged 20 p139
			Behaviours	
			E. Being protective	Absolutely... absolutely, [not addressing the TYAs end of life overtly] made it impossible because you were on eggshells all the time, not knowing if you were doing the right thing or the wrong thing.” Laura Mother of Ian who died aged 23 p126

		family members)	R. Placing TYA before self	“So I used to sleep downstairs with her.. it was just something that she wanted to do.. it had to be her way.. Ellen was very much in control.” Ann Mother of Ellen who died aged 23 p27
		Mixed method approach: qualitative research interviews, service evaluation questionnaires, and case studies	Unique experience of caring for and losing these TYA	
		Patient sample: 10 months – 26 years (data on 10 months - 15 year olds, and 26 year olds excluded from this review)	G. Experience of caregiver caring for and losing these TYA	“Ryan [aged 21] and I hadn’t really spoken about his death, no one had sat with us and really helped us to plan....if I had to do it again, I would want someone there that was specifically trained, you know, dealing with young people and saying, you know” he is gonna die, and you and I are going to spend an hour a week, or whatever, preparing for this.” Bianca p138
		Quality rating: High with limitations	Symptoms	
			F. Fear for the future	“He wanted it to be as it had always been, and it wasn’t, because it just wasn’t possible to be that way anymore. And that was his big fear, is that everything was going to fall apart.” Clare p139
			L. Isolation	“I was like, “I’m not letting him go”The rooms they showed us were really wonderful... and the nurses were really nice, but it was just...no one was his age there. There was nothing that I could relate to.” Bianca p67
			N. Physical symptoms	“And you know I thought he was going to die that night. I must admit, I didn’t sleep at all that night.” Joan Mother of Stuart who died aged 17 p130
Price, J, Jordan, J, Prior, L & Parkes, J 2011	Unimaginable loss: Contingent suicidal ideation in family members of oncology patients. (UK)	Qualitative (retrospective) Stratified purposeful sample Interpretive qualitative approach: In depth semi-structured interviews with purposeful sample of 25 recently bereaved parents. Themes	Behaviours	
			E. Being protective	“But we always felt that if he knew he was going to die it would destroy him” Caregiver for TYA 20 yrs. old, p1388
			R. Placing TYA before self	“Our family was Dan our life was Dan you didn’t do it consciously it was something had to be done Dan was everything to the family and everything was Dan you couldn’t make a decision without Dan it was Dan if it was going for the groceries to the youngsters going somewhere he was always taken into consideration.” Parent of boy age 19 with muscular dystrophy p1387
			Unique experience of caring for and losing these TYA	

		<p>identified from data. 25 bereaved parents of 16 children – child lost 6- 24 months previously</p> <p>Patient sample: 2 months – 20 years.</p> <p>Only 4 families where age of TYA was between 16 and 20 could be included in this review</p> <p>Quality rating: High with limitations</p>	G. Experience of caring for and losing these TYA	As R. Above Parent of boy age 19 with muscular dystrophy p1387
Peteet, J R, Maytal, G, Rokni, H	Unimaginable loss: Contingent suicidal ideation in family members of oncology patients. (U.S.A.)	<p>Case study (prospective)</p> <p>3 authors present and reflect upon 5 cases of potential contingent suicide where the medical team had felt challenged to consider psychiatric consultation. A single case reported where the TYA was identifiable as a mother of a 21-year-old woman who was dying in the intensive care unit from complications of a bone marrow transplant for acute myelogenous</p>	Behaviours	
			Q. Suicidal ideation	As her daughter's condition worsened, Mrs J told the chaplain that if her daughter died, she would settle her affairs, give away her dog and then kill herself p166

		<p>leukemia</p> <p>Quality rating: Moderate</p>		
Sobel, S, & Cowan, C 2003	'Ambiguous loss and disenfranchised grief: the impact of DNA predictive testing on the family as a system' (U.S.A.)	<p>Qualitative (prospective)</p> <p>Self-selected sample</p> <p>Thematic analysis of interview transcripts</p> <p>55 participants (18 families) ethnically homogeneous, all Caucasian, most of European decent and college educated</p> <p>Age range not stated</p> <p>Account of one individual identified as 'mother of a 21-year-old daughter who tested positive to Huntington disease was included in this review</p> <p>Quality rating: Moderate/High with limitations</p>	Symptom	
			P. Guilt and self blame	<p>"He (the father) was extremely upset because he felt he had done this to his daughter. He started to hate himself. I think he loathes himself and wants an excuse not to live anymore." p521</p>

Figure 2. Mind mapping to identify emergent themes from coded data

