Psychosocial Adjustment to Cancer in Younger Adults with Hodgkin Lymphoma or Testicular Cancer: Transitions to Survivorship

Lauren Elizabeth Matheson

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Abstract

Background: Cancer is an unexpected diagnosis in young adulthood, which can disrupt normal developmental milestones. Testicular cancer and Hodgkin lymphoma typically affect young adults, however relatively few studies have explored the psychosocial impact of these cancers. This thesis aimed to explore the process of psychosocial adjustment to these cancers in young adulthood in order to inform intervention development and service provision.

Methods: Patients who had completed treatment for testicular cancer or Hodgkin lymphoma were recruited from three hospitals in England through invitation from the clinical team. Qualitative semi-structured interviews were conducted over two time points in the year following treatment completion with 28 participants (18 testicular cancer and 10 Hodgkin lymphoma survivors), aged between 21-44 years old (22 male and 6 female). In total, 48 interviews were conducted. Data were analysed using grounded theory.

Findings: Positive psychosocial adjustment involved the overall process of *dismantling the current and future threats of cancer*, which entailed two transitions of *gaining a sense of perspective over the threats of cancer* and *striving to get on with life and restore normality*. The first transition was achieved by the processes of weighing up the significance of cancer, taking an active approach to overcoming the threats and positively reframing the threats of cancer. The second transition was achieved through the processes of accepting and normalising the threats of cancer, re-establishing a sense of security and letting go of fears, and preserving and enhancing a normal self. Negative psychosocial adjustment entailed two transitions; *losing a sense of perspective over the threats of cancer* (Transition 1) and *struggling to achieve a sense of normality after cancer* (Transition 2). The first transition included the processes of holding negative illness perceptions, taking a generalised view of cancer and adopting a stoical and silent approach. The second transition included the processes of struggling to accept the threats, losing a sense of security after treatment completion and ruminating on fears.

Conclusions: This theory highlights both positive and negative adjustment trajectories in young adult cancer survivors. This has implications for the development of psychosocial interventions aimed at supporting negatively adjusted patients. In particular, health professionals could promote adjustment through addressing negative illness beliefs, preparing patients for the transition to survivorship and facilitating peer support. Young adults exhibited preferences for informal psychosocial support, which has implications for the development of one-to-one peer mentoring interventions, as well as other interventions that may promote self-management.

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Chapter 1: Introduction

1.1 Current issues in cancer survivorship

Currently around 2.5 million people in the UK are living with or beyond a diagnosis of cancer, and this figure is projected to rise to 4 million by 2030 (Macmillan Cancer Support, 2015; Maddams, Utley and Moller, 2012). It is estimated that the lifetime risk of having a cancer diagnosis is 1 in 2 in people who are born after 1960 (Cancer Research UK, 2015a). While overall survival rates have increased over the last few decades, this varies considerably by cancer type, with 10-year survival rates at 1.1% for pancreatic cancer compared to 98.2% for testicular cancer (Cancer Research UK, 2015a; Quaresma, Coleman and Rachet, 2015). For cancer survivors as a whole, 50% of those diagnosed will survive for at least 10 years, which is double the rate compared to 40 years ago (Cancer Research UK, 2015a). However, cancer survivorship has been coined '*a pandemic of treatment success'* as cancer and its treatment may have many physical and psychosocial consequences for survivors, both short and long-term (Aaronson *et al.*, 2014; Barraclough, 1999; Earle, 2007; Wolff, 2007).

Compared to the UK population, cancer survivors may report worse physical health, akin to those with long-term conditions (Elliott *et al.*, 2011; Glaser *et al.*, 2013; Macmillan Cancer Support, 2015). Cancer survivors may also encounter ongoing symptoms such as pain and fatigue, issues with work participation, and psychological distress, often related to fear of recurrence (Aaronson *et al.*, 2014; Glaser *et al.*, 2013). In the last few years, cancer survivorship issues have become a priority for UK policymakers following the release of the National Cancer Survivorship Initiative (NCSI) (Department of Health, Macmillan Cancer Support and NHS Improvement, 2010). The NCSI has called for several key shifts in cancer survivorship care; a shift in emphasis from viewing cancer in an acute illness framework to a focus on wellbeing and recovery after cancer; holistic care; support for self-management; tailored follow-up care; and measuring patients' experiences and outcomes (Department of Health, Macmillan Cancer Support and NHS Improvement, 2010). More recently, promoting and sustaining recovery after cancer treatment have been outlined as key areas of importance, as well as managing the consequences of treatment (Department of Health, Macmillan Cancer Support and NHS Improvement, 2013). However, cancer survivorship is an emergent field of cancer research, and there has been a relative dearth of research focusing on the experience of cancer survivors (Feuerstein, 2007b). In the UK, the lack of high quality research investigating the psychosocial impact of living with cancer beyond treatment has been noted (Richardson *et al.*, 2011). In order to improve service provision, identifying the specific concerns, experiences and needs of cancer survivors at varying points along the disease journey as well as patients' experiences and preferences regarding care provision are recommended priorities for future research (Department of Health, Macmillan Cancer Support and NHS Improvement, 2013; Richards, Corner and Maher, 2011).

1.1.1 Transitions to survivorship

Definitions of cancer survivorship vary (Feuerstein, 2007a). Therefore for clarity in this thesis, the term 'cancer survivor' will be used for an individual who has been diagnosed with cancer and has completed initial treatment, regardless of prognosis. This is in line with the definitions adopted by UK policymakers (Department of Health, Macmillan Cancer Support and NHS Improvement, 2010). Studies propose a number of important transition points for patients along the cancer journey. One key transition occurs after completion of initial cancer treatment, also known as the '*re-entry'* phase. In the United States (US), a landmark report by the Institute of Medicine (IOM) '*From Cancer Patient to Cancer Survivor: Lost in Transition'* (Hewitt, Greenfield and Stovall, 2006) highlighted the inadequacies of supportive care for patients once treatment is completed. The IOM report stated that *"the transition from active treatment to post-treatment care is critical to long-term health"* (p.1) (Hewitt, Greenfield and Stovall, 2006). During treatment, patients have generally had intensive contact over a period of weeks or months with a range of health care professionals. Although the end of cancer treatment is often associated with a sense of relief (Lethborg *et al.*, 2000), patients have commonly reported feelings of abandonment when they are discharged and placed on a follow-up regimen, and miss the treatment routine and the 'safety net' of frequent contact with health professionals (Arnold, 1999; Foster *et al.*, 2009; Jefford *et al.*, 2008; Larsson, Hedelin and Athlin, 2007; Parry *et al.*, 2011). Patients may also encounter a loss of contact with other cancer patients, as well as diminished support from friends and family (Allen, Savadatti and Levy, 2009; Jefford *et al.*, 2008). During this transitional period, patients often have to deal with feelings of uncertainty, loss of confidence, heightened distress and feelings of vulnerability (Arnold, 1999; Foster and Fenlon, 2011; Foster *et al.*, 2009; Oxlad *et al.*, 2008; Richardson *et al.*, 2011; Thompson, Palmer and Dyson, 2009). Psychological needs have been reported as one of the most common unmet needs amongst UK cancer survivors, particularly dealing with fear of recurrence (Armes *et al.*, 2009; Lobb *et al.*, 2009). Once treatment is over, survivors may feel anxious, unsupported and unprepared for survivorship (Cappiello *et al.*, 2007; Corner *et al.*, 2013; Parry *et al.*, 2011). They may also encounter ongoing issues with fatigue and body image, difficulties in resuming their previous roles, returning to work and financial concerns (Allen, Savadatti and Levy, 2009; Foster and Fenlon, 2011). Importantly, survivors may also lack confidence to seek support for these issues (Foster and Fenlon, 2011; Foster *et al.*, 2009). Yet patients' experiences and needs during this period of transition are areas that have received relatively limited attention in the literature. This relatively small but growing body of research examining end of treatment experiences has mostly focused on breast cancer patients (Allen, Savadatti and Levy, 2009; Cappiello *et al.*, 2007; Kantsiper *et al.*, 2009; Oxlad *et al.*, 2008), with a few studies examining haematological cancers (Parry *et al.*, 2011), colorectal cancer (Simpson and Whyte, 2006), head and neck cancer (Larsson, Hedelin and Athlin, 2007) and some with mixed cancers (Armes *et al.*, 2009). Previous studies are limited by very small sample sizes, poor methodological quality and have seldom explored this topic in the UK healthcare setting (Foster and Fenlon, 2011). In a prospective study, 30% of survivors reported at least five unmet needs at the end of treatment, which persisted in the majority (60%) of these survivors at six month follow-up (Armes *et al.*, 2009). Arguably, the current system of care is not meeting the needs of this growing population of survivors, particularly with regards to follow-up care, which has traditionally been focused on medical surveillance for recurrences rather than holistic support (Armes *et al.*, 2009; Department of Health, Macmillan Cancer Support and NHS Improvement, 2013; Jefford *et al.*, 2013).

In light of this existing evidence, studies have called for the need for health professionals to better prepare patients for this transition, such as through providing an exit interview prior to discharge, a treatment summary and personalised care plan as well as sign-posting and support with ongoing side effects (Hewitt, Greenfield and Stovall, 2006; Larsson, Hedelin and Athlin, 2007; Lobb *et al.*, 2009; Parry *et al.*, 2011). The NCSI outlined that "*this period is particularly important as a time for empowering patients towards supported self-management"* (p.61) (Department of Health, Macmillan Cancer Support and NHS Improvement, 2013). Although several definitions have been put forward, McCorkle et al., (2011) usefully defined self-management as "*those tasks that individuals undertake to deal with the medical, role, and emotional management of their health condition(s)* (p.51). Therefore, the need to design interventions to further support survivors to self-manage following treatment completion has been highlighted, such as interventions which may enhance survivors' self-efficacy to manage ongoing symptoms and side effects as well as promote adjustment to cancer (Foster and Fenlon, 2011; Jefford *et al.*, 2008). More evidence is needed to inform the re-design of follow-up care and service provision for survivors in order to better meet the needs of this growing population.

1.1.2 Defining adjustment

Recently, in light of the increasing numbers of individuals living with long-term conditions, Huber *et al.,* (2011) argued that health should be defined in terms of an individual's ability to adapt and self-manage the challenges of illness, rather than in terms of 'complete' well-being or quality of life. Achieving a sense of health was described as "*an active process of continuous adjustment, a subtle equilibrium between our physiological, psychological and spiritual integrity and the outer or inner influences that can strengthen or undermine this"* (p.2) rather than as a "*steady state"* (Alivia, Guadagni and Roberti di Sarsina, 2011). Similarly, a recent statement from the NCI (2014) defined adjustment to cancer as "*an ongoing process in which the individual patient tries to manage emotional distress, solve specific cancer-related problems, and gain mastery or control over cancer-related life events. Adjustment to cancer is not a unitary, single event but rather a series of ongoing coping responses to the multiple tasks associated with living with cancer"* (p.5). According to the NCI (2014), the potential for adjustment 'crises' can be around the transitional points of diagnosis, treatment, post treatment or remission phase. Meleis *et al*., (2000) propose that people undergoing transitions tend to be more vulnerable to risks that may in turn affect their health, suggesting that *'uncovering these risks may be enhanced by understanding the transition process'* (p.1). Yet the concept of adjustment in the cancer literature has often been used to describe the presence or absence of psychological morbidity at one time point, as opposed to a process of change over time (Sharpe and Curran, 2006). There have also been inconsistencies in the way that adjustment has been defined, with different researchers using a range of outcomes, such as the absence of psychological distress or anxiety, good quality of life, positive affect or wellbeing (Sharpe and Curran, 2006). More recently there has been a paradigm shift from research identifying factors involved in poorer adjustment to a greater emphasis on identifying those involved in promoting positive adjustment (de Ridder *et al.*, 2008). It is important to understand how some patients adjust well rather than develop psychological disorders following cancer, despite the many threats posed by the disease, and why others are adversely psychologically affected (Brennan, 2001; Costanzo, Ryff and Singer, 2009; Sansom-Daly and Wakefield, 2013). Further understanding of the mechanisms involved in this process will be able to usefully inform interventions to promote adjustment (Stanton *et al.*, 2013).

In summary, understanding the challenges involved in cancer survivorship is now a research priority. In particular, greater understanding is needed regarding how patients manage and adjust to the transitional phase of treatment completion, in order to guide the design of services and interventions for this growing population.

1.2 The psychosocial challenges for younger adult cancer survivors: overview of the literature

1.2.1 Overview

In recent years, there has been increasing recognition that younger adult cancer survivors are a distinct and potentially more vulnerable group, who have unique challenges, experiences, health behaviours and needs (Grinyer, 2007; Haase and Phillips, 2004; Hall *et al.*, 2012; Kelly and Gibson, 2008; Zebrack, 2009; Zebrack and Isaacson, 2012). Data from the US shows that the most common cancers affecting 15-39 years olds include germ cell tumours, such as testicular cancer, and leukaemia, lymphoma, thyroid carcinoma, bone and soft tissue sarcoma, cervical cancer, breast cancer, colorectal carcinoma, and central nervous system tumours (Adolescent and Young Adult Oncology Progress Review Group, National Cancer Institute and LIVESTRONG Young Adult Alliance, 2006). Every year in the UK, around 1000 cancer cases are diagnosed in adults between 15-24 years, and around 11,000 men and 21,000 women are diagnosed in the 25-49 year age group (Cancer Research UK, 2013a). In the UK, the most common cancers in the 25-49 year old ‘middle adult’ group are testicular cancer (15%), malignant melanoma (11%) and bowel (9%) in males, and breast cancer (45%), malignant melanoma (9%) and cervical cancer (9%) in females (Cancer Research UK, 2013a). Survival rates for cancers that peak in younger adulthood lag behind survival rates for cancers that peak in childhood and older adulthood, although there is wide variation in survival between cancer types (Bleyer, 2011). Amongst several possible contributing factors is a delayed diagnosis, as cancer is not expected in this age group by both young adults themselves and health professionals, who may fail to recognise symptoms (Adolescent and Young Adult Oncology Progress Review Group, National Cancer Institute and LIVESTRONG Young Adult Alliance, 2006). It has also been suggested that this may also be due to the lack of attention given to younger adults by health professionals as well as researchers, such as fewer clinical trials in this age group (Bleyer, Budd and Montello, 2006). Male younger adult survivors also have poorer survival than females, which has also been found in the wider literature for adults as a whole and may be explained by riskier health behaviours in males (Bleyer, 2011; Courtenay, 2000f). The incidence of cancers in younger adults is on the rise, particularly for germ cell tumours and carcinomas (Cancer Research UK, 2013d; National Cancer Institute, 2006). In recent years, policy makers and researchers in the UK and abroad have called for an increase in knowledge regarding the unique psychosocial challenges that younger adults with cancer may face (Adolescent and Young Adult Oncology Progress Review Group, National Cancer Institute and LIVESTRONG Young Adult Alliance, 2006; Department of Health, Macmillan Cancer Support and NHS Improvement, 2013; Soliman and Agresta, 2008; Taylor *et al.*, 2013).

Diagnosis and treatment of cancer can significantly disrupt normal milestones or transitions during younger adulthood, such as leaving home, finishing education, finding a partner, parenthood and work (Bellizzi *et al.*, 2012; Grinyer, 2007; Grinyer, 2009; Zebrack, 2011). Concerns regarding appearance and body image, sexuality and identity development, caring for young children, financial issues, establishing independence from parents, and health-related concerns towards the future may be particular challenges for younger adult survivors (Bellizzi *et al.*, 2012; Kelly and Gibson, 2008; Zebrack, 2011; Zebrack and Isaacson, 2012). Compared to the general population, young adult cancer survivors have also displayed worse health-related quality of life (Quinn *et al.*, 2015; Smith *et al.*, 2013h; Tai *et al.*, 2012). The transition from treatment to survivorship may hold particular psychological and physical challenges for younger adults (Keim-Malpass and Steeves, 2012; Thompson, Palmer and Dyson, 2009). Previous studies have tended to look at adult cancer survivors as a whole or focused on childhood cancer survivors. Therefore, the literature focusing on young adult survivors is only recently emerging, and is gaining increasing recognition as a distinct speciality (Williams, 2013; Zebrack *et al.*, 2014a).

A scoping review of the literature on the psychosocial challenges for younger adult cancer survivors was undertaken in order to give an overview of existing research and highlight gaps in the knowledge base. The review in this chapter focused on studies published within the last 20 years on patients diagnosed during young adulthood and includes literature about survivors of all types of cancer. Following a systematic search, topic headings were guided by key issues in the literature, which will be discussed in turn.

1.2.2 The negative and positive psychological impact

While cancer can be distressing at any age, younger adult survivors may be at higher risk of psychological distress, such as depression and anxiety, in comparison to older cancer survivors (Costanzo *et al.*, 2007; Costanzo, Ryff and Singer, 2009; Harrison and Maguire, 1995; Kwak *et al.*, 2013; Mor, Allen and Malin, 1994; Parker *et al.*, 2003). Risk of psychological distress in younger adults may be influenced by disruption to education, work and significant life goals, as well as lowered resiliency in younger adults compared to older survivors (Costanzo, Ryff and Singer, 2009; Kwak *et al.*, 2013). Younger adult cancer survivors have also been shown to exhibit higher levels of distress in relation to comparison groups, such as siblings or age-matched controls (Salsman *et al.*, 2014), although some evidence suggests comparable results (Sansom-Daly and Wakefield, 2013). In one review, the prevalence of clinically significant distress ranged between 5%-57% across studies, of which most focused on post-traumatic stress symptoms (PTSS) (Sansom-Daly and Wakefield, 2013). Elsewhere, another review found that the prevalence of post-traumatic stress disorder (PTSD) ranged from 0-34.8% or between 4.4-78% for PTSS, although childhood and adolescent cancer survivors were included in both of these reviews (Sansom-Daly and Wakefield, 2013; Vuotto *et al.*, 2015). In terms of depression, rates reported ranged from 5%-24%, while the prevalence of anxiety ranged between 12-23% across studies (Sansom-Daly and Wakefield, 2013). This variation is likely to be accounted for by variations in cancer types, sample sizes and outcome measures used.

Younger adult cancer survivors are more likely to use mental health services compared to older survivors, although this may reflect differences in illness-related behaviour and greater needs regarding uncertainty about the future (Hall *et al.*, 2012; Hewitt and Rowland, 2002). Younger adults may also be more likely to report unmet needs compared to older adults (Armes *et al.*, 2009). In a Swedish sample, younger survivors under 30 years were at elevated risk of suicide (relative risk 1.6), especially in the first year after diagnosis (Lu *et al.*, 2013). Survivors in the Lu *et al.* (2013) study with a poorer prognosis were at greater risk, although other studies suggest that the prevalence of distress is unrelated to the type of cancer or prognosis (Kwak *et al.*, 2013; Sansom-Daly and Wakefield, 2013). Studies on the role of treatment-related variables in distress have yielded mixed findings, although the presence of iatrogenic late effects may be associated with distress (Sansom-Daly and Wakefield, 2013).

In terms of the association with demographic variables, mental health was found to be significantly worse in unmarried young adults (Smith *et al.*, 2013h) or if survivors reported an interruption to their education or careers (Yanez *et al.*, 2013). Studies have frequently shown that females are at greater risk of distress, as well as those on lower incomes or with low educational achievement (Sansom-Daly and Wakefield, 2013; Vuotto *et al.*, 2015). Distress may be elevated at diagnosis then decrease over time, yet may increase around the end of treatment transition (Kwak *et al.*, 2013). In young adults, this may be partially explained by the finding that while psychological resources may be high at the start of treatment, they may lessen over the course of treatment in terms of levels of optimism, locus of control and self-esteem (Pinquart, Frohlich and Silbereisen, 2007). During the transition to survivorship, fear of recurrence and uncertainty over the future may be particularly salient for younger adults (Kelly and Gibson, 2008; Shine Cancer Support, 2013; Thompson, Palmer and Dyson, 2009). A sense of uncertainty centred around fear of relapse, the duration of side effects, late effects and the impact on their children (Shine Cancer Support, 2013). After treatment, 61% of young adults felt they had lost a sense of security (Shine Cancer Support, 2013). Over the first year post diagnosis, 12% reported chronic distress throughout this period and a further 15% had delayed psychological distress (Zebrack *et al.*, 2014d). Distress also appeared to be worsened if psychological needs were not met over time (Zebrack *et al.*, 2014d).

While PTSD can be an issue for younger adults, they can also report post traumatic growth (PTG) and positive psychosocial outcomes following cancer, such as an increased self-confidence, improved relationships, empowerment, greater appreciation of life and sense of purpose (Park and Blank, 2012; Taylor *et al.*, 2013; Zebrack *et al.*, 2014a). One study found that positive outcomes may be found alongside negative outcomes (Bellizzi *et al.*, 2012).

1.2.3 Fertility and parenthood

Cancer treatment may affect the production of sperm in males throughout their lives or the maturation of ovarian follicles and ovulation in reproductive-age females (Kelly and Gibson, 2008; Schover, 2008). For women with depleted ovarian reserve at the start of treatment, some types of chemotherapy can cause complete ovarian failure; women who have a greater ovarian reserve may enter premature menopause as a result of certain chemotherapy treatments (Levine, 2012). Fertility preservation is much more complex, time consuming, costly and invasive for females, as sperm banking is generally considered straightforward in males (Kelly and Gibson, 2008; Soliman and Agresta, 2008). The most successful method of fertility preservation in women is ‘in vitro fertilisation’ (IVF) with cryopreserved zygotes, which requires sperm donation (Soliman and Agresta, 2008). Women without a partner and unwilling to choose a sperm donor at the time of oocyte harvesting have the option of undergoing alternative options, such as oocyte cryopreservation, although this is less effective (Soliman and Agresta, 2008). Fertility issues may influence wellbeing and future plans of younger adults, and may negatively impact on relationships (Crawshaw, 2013; Gorman *et al.*, 2012). The threat to parenthood has been found to be more distressing than the diagnosis itself (Grinyer, 2009) and distress over an unfulfilled desire for children may persist for many years (Canada and Schover, 2012).

The information and support given to younger adult survivors in the UK regarding fertility appears to be patchy, particularly regarding options for preservation given before treatment (Absolom *et al.*, 2009; Adams, Hill and Watson, 2013; Grinyer, 2009; Shine Cancer Support, 2013; Wright *et al.*, 2014), so fertility concerns have emerged as a key area of unmet need for younger survivors (Absolom *et al.*, 2009; Penrose *et al.*, 2012; Tschudin and Bitzer, 2009; Yee *et al.*, 2012; Zebrack, 2009; Zebrack, Mills and Weitzman, 2007). In one review, the percentage of those who had received fertility counselling ranged between 34-72% of survivors across studies (Tschudin and Bitzer, 2009). Health professionals have been found to be less likely to offer fertility preservation to female survivors over 35 years, with low education or ethnic minority backgrounds (Crawshaw, 2013; Letourneau *et al.*, 2012). However, late presentation may be more common in patients from lower socio-economic status or ethnic groups (Ward *et al.*, 2004; Woods, Rachet and Coleman, 2006). Delays in presentation or a diagnosis of aggressive cancer may mean that patients need imminent treatment and so fertility preservation may be risky (Kim, 2006; Wallace, Anderson and Irvine, 2005). There may be barriers to having discussions over fertility preservation for oncologists including; lack of knowledge and time as well as perceiving a poor success rate of fertility preservation techniques (Adams, Hill and Watson, 2013). Importantly, around half of UK younger adults, particularly females, felt that before treatment, they could have been better supported to preserve fertility (Armuand *et al.*, 2015; Shine Cancer Support, 2013; Wright *et al.*, 2014; Yeomanson, Morgan and Pacey, 2013). Quantitative and qualitative work has shown that perceptions of fertility issues rather than actual fertility status or survivors' age or stage in life were more likely to be related to quality of life, wellbeing and psychological morbidity (Crawshaw *et al.*, 2009; Sobota and Ozakinci, 2014). Younger survivors may be unaware of their fertility status, and may even assume that they are infertile (Gorman *et al.*, 2012; Penrose *et al.*, 2012; Wright *et al.*, 2014). Female survivors may report a sense of difference to their healthy peers, especially from pregnant friends, and may also report a sense of urgency about having children, due to feeling their time to conceive was limited (Halliday, Boughton and Kerridge, 2014). Males may also report worries and uncertainty regarding their fertility status (Chapple *et al.*, 2007) although fewer studies have explored the impact on male survivors. In order to address unmet needs surrounding fertility, studies have suggested that younger cancer survivors want tailored information, open and proactive discussions initiated by health professionals, a written summary, referral to a fertility specialist and counselling if needed as well as advice at the end of treatment on contraception use and pregnancy risk (Crawshaw, 2013; Patterson *et al.*, 2012; Wilkes *et al.*, 2010; Wright *et al.*, 2014). A lack of adequate information can be distressing as the impact of fertility can have long-term repercussions for survivors (Grinyer, 2009).

1.2.4 Relationships and social support

Few studies have examined the impact of cancer on relationships between younger adults and their significant others (Kent *et al.*, 2013; Taylor *et al.*, 2013). For younger adults, there may be issues with renegotiating independence with parents, as they may have had to become financially and physically dependent on their parents during treatment or move back into the family home (Kelly and Gibson, 2008; Lewis *et al.*, 2013). Young adults may also report a lack of support for their partners (Shine Cancer Support, 2013). Single participants may report issues with dating after cancer, especially regarding when to disclose their diagnosis to a future partner (Shine Cancer Support, 2013; Zebrack and Isaacson, 2012). Research has shown that peer support is highly important for younger adults (Fern *et al.*, 2013; Kent *et al.*, 2011; Taylor *et al.*, 2013; Tindle, Denver and Lilley, 2009; Tsangaris *et al.*, 2014). Some younger survivors have reported isolation as friendships had been lost due to cancer and some felt that support from a ‘buddy’ or someone who had been through a similar experience would be helpful (Kent *et al.*, 2011; Patterson *et al.*, 2012; Shine Cancer Support, 2013; Tindle, Denver and Lilley, 2009). One study found that 43% wanted to meet other peer survivors, which was a strong need for survivors with a greater symptom burden, those in their 20’s, and who perceived an impact on their relationships due to cancer (Kent *et al.*, 2013). UK young adults stressed the importance of peer support in a natural environment and conversations that were normal, sometimes disliking health professional involvement in this area (Fern *et al.*, 2013; Taylor *et al.*, 2013).

1.2.5 Work and finances

Cancer may also disrupt younger survivors’ efforts at establishing careers and employment, as well as adding a financial burden (Bellizzi *et al.*, 2012; Sharpe, 2011). A lack of research examining younger adults experiences of work has been noted (Sharpe, 2011; Taylor *et al.*, 2013). In one study, whilst the majority (72%) of younger adults who were previously working before diagnosis returned to work or school following treatment, a significant number reported difficulties with work, such as ‘forgetting’ (50%) or ‘keeping up with work or studies’ (30%) (Parsons *et al.*, 2012). Elsewhere, 13% were unable to work at all, 53% felt they were unable to work in the same way after cancer, and a third were unable to work full-time (Shine Cancer Support, 2013). Younger adults have also reported feeling pressurised into returning to work due to financial concerns and some felt marginalised at work (Sharpe, 2011). Returning to work may provide positive benefits such as regaining a sense of normality, easing financial pressures, improving quality of life and may bring about a renewed sense of health and the feeling that adulthood is resumed (Kennedy *et al.*, 2007; Peteet, 2000; Sharpe, 2011). However, younger adults may exhibit parallel feelings about resuming work; whilst feeling that they achieve more from their working lives, this may also run alongside the notion that there is '*more to life than work'* (Sharpe, 2011). Financial issues such as debt were reported in 30% and a similar number reported a smaller income after cancer, and some found it hard to obtain life insurance (Shine Cancer Support, 2013). These survivors described a need for information to be given to employers as well as guidance on returning to work and help in the form of mentoring (Shine Cancer Support, 2013).

1.2.6 Body image and identity renegotiation

Cancer treatment can lead to changes to the body, such as alopecia, weight gain or loss of muscle bulk, which may threaten body image and self-identity (Kelly and Gibson, 2008; Zebrack, 2011; Zebrack *et al.*, 2014a) and is a particularly salient concern for younger adults (Bellizzi *et al.*, 2012; Harrison and Maguire, 1995). Following changes to identity and body image, younger adults may also experience the loss of sexual confidence (Kelly and Gibson, 2008; Shine Cancer Support, 2013) and exhibit support for sexual issues (Geue *et al.*, 2015). Qualitative research shows that young adults find hair loss particularly troublesome and may struggle to accept this issue (Snöbohm, Friedrichsen and Heiwe, 2010; Tindle, Denver and Lilley, 2009). In a small sample of survivors, the detrimental impact on body image remained long after treatment completion (Tindle, Denver and Lilley, 2009).

After treatment, the re-establishment of identity may be a challenge (Fern *et al.*, 2013; Patterson *et al.*, 2012). Younger adults may therefore report a need for identity renegotiation after cancer in order to re-establish their autonomy and independence (Patterson *et al.*, 2012). Achieving a sense of normalcy after treatment completion was shown to be a key goal of younger adults, which is similar to research conducted on young people with other health conditions (Grinyer, 2007; Kumar and Schapira, 2013; Miedema, Hamilton and Easley, 2007; Taylor *et al.*, 2013). The premature confrontation with mortality may mean that young survivors will have to re-define the meaning of normality (Kelly and Gibson, 2008). This may be a 'new normal' or one in which their 'pre cancer' life has continued (Miedema, Hamilton and Easley, 2007; Patterson *et al.*, 2012).

1.2.7 Areas for future research

Several key areas warrant further investigation. Firstly, the impact of the end of treatment transition on distress in younger adults is poorly understood. Further studies are needed to explore the changes in distress levels and emotional challenges across the cancer trajectory in younger adults using longitudinal methodologies (Kwak *et al.*, 2013). Further research is also needed into the processes involved in psychological adjustment trajectories in younger adults, which may help inform intervention development (Sansom-Daly and Wakefield, 2013). More research into the positive outcomes derived from cancer in younger adulthood may also shed light on the process of adjustment. Further exploration of survivors' perceptions towards fertility is also warranted, as this has shown to influence adjustment outcomes, and little is known about why some survivors may adjust well to this issue, while others do not (Sobota and Ozakinci, 2014). Studies are also needed to explore how younger adults cope with the threat to their fertility. Fertility concerns may also change over time (Grinyer, 2009), so further research is needed to explore the trajectory of fertility related needs. Further investigation into the impact of cancer on romantic relationships and how younger adults manage relationships with their spouses, peers and children is needed, especially the support needs of single survivors. Further studies in the UK setting would be useful, particularly regarding work related issues, as many studies are based in the US or Canada, where issues such as health insurance may influence the impact of cancer (Parsons *et al.*, 2012; Sharpe, 2011). Further research is also needed on the specific issues encountered once younger adults return to work. Body image and identity issues are also under researched areas and more evidence is needed regarding what would promote adjustment to body image and how young adults renegotiate their identities after cancer (Snöbohm, Friedrichsen and Heiwe, 2010).

1.2.8 Focusing on survivors of specific cancer types

Most studies in this area have included a range of cancer types which have different prognoses and treatment regimens. Zebrack (2009) recommends that more studies examine the needs of younger adult survivors with specific cancer sites. One of the most prevalent cancers in younger men is testicular cancer (Bleyer, Viny and Barr, 2006; Cancer Research UK, 2015p); and

Hodgkin lymphoma is a cancer prevalent in both men and women in younger adulthood (Bleyer, Viny and Barr, 2006; Cancer Research UK, 2014g). These two cancers both have favourable prognoses and high survival rates (Cancer Research UK, 2014n; Cancer Research UK, 2015p) and several previous studies have combined these two populations of survivors (Bloom *et al.*, 1993; Dohle, 2010; Hannah *et al.*, 1992; Jonker-Pool *et al.*, 2004; Robitaille, 2010). This thesis will focus on survivors of these cancers, for which there is a relatively limited published literature in the psychosocial field (see Chapters 2 and 3).

1.2.9 Conclusions

The experience of young adult cancer survivorship is still a relatively under-researched area. While research in this field is emerging, many gaps are still evident. It is apparent that whilst the majority of younger adults are able to adjust well, a subgroup display psychological distress so further research could usefully examine the process of adjustment and what may promote recovery. Identifying the pathway of adjustment to cancer in young adulthood will highlight how those struggling to adjust could be identified and supported. Further exploration into issues surrounding younger adulthood is also warranted, especially key areas including fertility issues, social support and relationships, work and finances as well as body image and identity issues. Further research exploring the experiences, beliefs and needs of younger adults is also needed, and investigating issues amongst survivors recovering from specific cancer types may be particularly useful. The literature on this population is also predominately quantitative with relatively fewer qualitative studies. Due to the dearth of interventions in this area, qualitative approaches will be important for informing the development of future psychosocial interventions and service provision to better address the needs of this population. This thesis will address this deficit of research and explore these issues in younger adult cancer survivors.

1.3 Outline of the thesis

The following two chapters (Chapters 2 and 3) review the literature exploring the psychosocial impact of testicular cancer and Hodgkin lymphoma. These are followed by a Methods chapter (Chapter 4), which describes the grounded theory methodology employed in the study and methods used to collect and analyse data. This is followed by a short chapter presenting the theory of adjustment to cancer in young adulthood as well as the background information of the two samples (Chapter 5). The next two chapters use the framework of the theory of adjustment to cancer to present the findings of the qualitative interview study, first regarding the experiences of young adults with testicular cancer (Chapter 6), followed by those of young adults with Hodgkin lymphoma (Chapter 7). The final chapter is the Discussion (Chapter 8) followed by the Reference list and Appendices.

1.4 Aims and Objectives

1.4.1 Aim

The overall aim of this study is to develop a detailed understanding of how young adults adjust to the psychosocial impact of cancer, (specifically to

Hodgkin lymphoma or testicular cancer), particularly during the transition from treatment to follow-up.

1.4.2 Objectives

The specific objectives of the study were to:

- Explore the psychosocial impact of having cancer in young adulthood.
- Examine how young adult cancer survivors experience the transition from treatment to follow-up and how they adjust to being discharged from hospital care.
- Explore how survivors cope and adjust to the psychosocial impact, specifically during the transition from treatment to follow-up.
- Elicit survivors' perceptions of their supportive care or information needs following treatment completion.
- Examine adjustment patterns across two time points in the first year following treatment completion and develop a theory of adjustment to explain the processes involved in this transition.

Chapter 2: A Literature Review of the Psychosocial Impact of Testicular Cancer

2.1 Background

2.1.1 Incidence and risk factors

While testicular cancer is a relatively rare disease, it is the most common cancer in younger men aged 15 to 49 years, and approximately 2,200 men in the UK are diagnosed with the disease each year (Beyer *et al.*, 2013; Cancer Research UK, 2015p). The lifetime risk of developing testicular cancer is now 1 in 200 for men in the UK (Cancer Research UK, 2015h). In contrast to other cancers, testicular cancer is most likely to affect men in the prime of their lives, as the incidence peaks around 30-34 years, with men under 35 years accounting for around 50% of all cases (Cancer Research UK, 2015h; Dearnaley, Huddart and Horwich, 2001). Since the 1970's there has been a rising trend in the numbers of men being diagnosed with testicular cancer, although incidence rates have been relatively stable in the UK since 2000 (Cancer Research UK, 2015h; Le Cornet *et al.*, 2014). Elsewhere, particularly in Southern European countries, there is a rising trend in diagnoses, which is expected to continue in the future (Dearnaley, Huddart and Horwich, 2001; Khan and Protheroe, 2007; Le Cornet *et al.*, 2014). Yet the reasons behind the rising number of cases is still poorly understood (McGlynn *et al.*, 2003; Shanmugalingam *et al.*, 2013b). Environmental factors are thought to play a role, such as higher oestrogen concentrations in utero (Khan and Protheroe, 2007).

The majority (95%) of testicular cancers are germ cell tumours (GCT), of which around 40-45% are seminomas (SGCT) and 40-45% are non-seminoma tumours (NSGCT), including teratomas, embryonal carcinoma or yolk sac tumours (Cancer Research UK, 2015h; Horwich, Nicol and Huddart, 2013). The incidence of SGCT is higher in the 30-45 age group, whereas NSGCT are more often diagnosed in the 20-35 age group (Cancer Research UK, 2015h). Around 15% of GCT are a combination of both subtypes, and are classified as NSGCT (Cancer Research UK, 2015h; Vasdev, Moon and Thorpe, 2013). A small minority of testicular tumours are non-Hodgkin lymphomas, although these are most commonly found in men over 50 (Koukourakis and Kouloulias, 2010).

Men who are Caucasian, live in developed countries, have a first degree family relative with testicular cancer (6-10% increased risk), had undescended testicles at birth (2-4% increased risk), or who have pre-existing infertility and abnormal semen (20% increased risk) are at greater risk of the disease (Cancer Research UK, 2014v; Chia *et al.*, 2008; Khan and Protheroe, 2007; Raman, Nobert and Goldstein, 2005; Rosen *et al.*, 2011; Shanmugalingam *et al.*, 2013a). Research has examined other potential risk factors, including human immunodeficiency virus (HIV), tallness, previous marijuana use, having had a vasectomy or mumps, but the evidence to date is inconclusive (Vasdev, Moon and Thorpe, 2013).

2.1.2 Symptoms and diagnosis

Several symptoms indicate the possible presence of localised testicular cancer, including a painless lump in the testicle, swelling, hardening or pain in the scrotum and a heavy scrotum (Cancer Research UK, 2014ac; Vasdev, Moon and Thorpe, 2013). If the disease has spread, men may present with lower back pain, difficulty swallowing or breathing (Cancer Research UK, 2014ac). In advanced disease, symptoms include weight loss, neck mass, cough, nausea or vomiting (Khan and Protheroe, 2007). Diagnostic delays are not uncommon and reasons for delay include lack of awareness, embarrassment, perceived lack of time, fear of cancer or of appearing 'weak' or a hypochondriac (Cancer Research UK, 2014ac; Chapple, Ziebland and McPherson, 2004; Gascoigne, Mason and Roberts, 1999; Horwich, Nicol and Huddart, 2013; Khan and Protheroe, 2007). The majority of men will have just one affected testicle, with 1-2% presenting with bilateral testicular cancer (Vasdev, Moon and Thorpe, 2013). Around 10% of men will present at accident and emergency centres, and these men will have poorer survival chances, compared to those presenting in primary care (NHS England, 2013). There is currently no screening program for testicular cancer; however there have been many awareness campaigns through testicular cancer charities, such as the recent Twitter campaign '*Nutnominate*' to encourage men to check their testicles regularly.

Following diagnosis, testicular cancer will be broadly classified into three stages: stage I (cancer in the testicle only), stage II (cancer spread to lymph nodes in the abdomen) and stage III (cancer spread above the diaphragm, such as to the lungs or brain) (Vasdev, Moon and Thorpe, 2013). Around 75-80% of SGCT and 55% of NSGCT will be stage I at presentation (Albers *et al.*, 2012; Vasdev, Moon and Thorpe, 2013). Men with stages II or III for both NSGCT and SGCT are classified into either a good (90% of SGCT and

56% of NSGCT cases), intermediate (10% of SGCT and 28% of NSGCT cases) or poor prognosis (16% of NSGCT cases only) (Albers *et al.*, 2012; Vasdev, Moon and Thorpe, 2013).

2.1.3 Treatment

All men with testicular cancer will undergo a radical orchidectomy (surgical removal of the testes), and the type, stage and prognosis of testicular cancer determines whether patients also receive additional chemotherapy, radiotherapy, surgery or androgen deprivation treatment (Beyer *et al.*, 2013; Cancer Research UK, 2015t; Khan and Protheroe, 2007). In around half of patients, particularly those with stage I disease, only surgery is required (Fossa, Oldenburg and Dahl, 2009). Patients will then be managed by surveillance or ‘watch and wait’ following orchidectomy, with some patients with stage I disease receiving adjuvant treatment (Behringer *et al.*, 2013; Cancer Research UK, 2015t; Chung *et al.*, 2010). For men with stage I disease, there is no standard protocol for adjuvant treatment; however research suggests that survival outcomes are the same for men regardless of whether treatment adjuvant to orchidectomy is given (Chung *et al.*, 2010; de Wit, 2014; Dearnaley, Huddart and Horwich, 2001). Patients who are placed on surveillance and do not receive adjuvant chemotherapy may receive more intensive follow-up and have more exposure to radiation due to radio-imaging examinations (Vasdev, Moon and Thorpe, 2013). These patients may also have a slightly higher risk of recurrence for which the treatment is more intense, so these disadvantages will have to be considered against the advantages of surveillance, namely the avoidance of toxic treatment regimens and their short and long term effects (Khan and Protheroe, 2007).

There may also be issues with adherence, as men on surveillance were found to be significantly less adherent to attending follow-up appointments (77%) than those who received treatment (93%), although more recent evidence is warranted (Young *et al.*, 1991). For men with stage I disease, the drug carboplatin is often used for SGCT cases, and patients with NSGCT will often receive a combination of bleomycin, etoposide and cisplatin (BEP) cytotoxic drugs (Cancer Research UK, 2015t). Side effects of this chemotherapy regimen include nausea, vomiting, alopecia and fatigue (Fosså *et al.*, 2003; Fossa, Oldenburg and Dahl, 2009). Men with more advanced disease will receive one or more of these additional treatment regimens, and some may undergo retroperitoneal lymph node dissection surgery (Beyer *et al.*, 2013). Once treatment is over, patients are placed on a follow-up regimen, often for five years following treatment, which varies considerably depending on the disease type and stage (Albers *et al.*, 2005). There is currently a lack of consensus regarding 'best practice' for testicular cancer follow-up, with variations existing between UK hospital clinics (van As *et al.*, 2008).

2.1.4 Survival

The survival rate for testicular cancer is excellent and it is currently the most curable cancer in the UK (Cancer Research UK, 2014w). The improvement in survival rates has largely been due to the advances in cisplatin-based chemotherapy introduced in the 1970's, when the survival rate was approximately 70% (Einhorn, 1997; Sonneveld *et al.*, 2001; Travis *et al.*, 2010). Testicular cancer has subsequently been coined an *'oncology success story'* as 98.2% of men will survive for at least 10 years after diagnosis

(Cancer Research UK, 2015p; Quaresma, Coleman and Rachet, 2015). In fact, survival rates plateau after five years, so men who have survived over five years are effectively considered cured (Cancer Research UK, 2014w). The survival rate for testicular cancer is related to the stage of disease at diagnosis (Vasdev, Moon and Thorpe, 2013). Men who are diagnosed at stage III have an 84% chance of five year survival, compared to those at stage I, who have a 100% chance (Cancer Research UK, 2014w). Diagnostic delays have been shown to be highly associated with poorer survival (Huyghe *et al.*, 2007).

The risk of relapse is dependent on the type of testicular cancer (SGCT or NSGCT) and the stage of disease (Khan and Protheroe, 2007). Most relapses of testicular cancer will occur within the first two years following treatment completion (Albers *et al.*, 2005; Ehrlich and Baniel, 2007; Nolan *et al.*, 2010); ranging from a 10% risk in the first four years for men diagnosed at Stage I to 50% for men diagnosed with advanced disease (Khan and Protheroe, 2007). The risk of a secondary malignancy in the remaining testicle is between 0.8-5% (Zequi *et al.*, 2012).

2.1.5 Long-term physical morbidity

Despite the high cure rates, testicular cancer treatment, particularly BEP chemotherapy, may result in physical morbidity (Travis *et al.*, 2010). While treatment related effects may abate over time, 20-25% of men may have ongoing issues with neuropathy, tinnitus and Raynaud phenomena one year after chemotherapy (Fossa, Oldenburg and Dahl, 2009). Treatment may also increase the risk of late cardiovascular toxicity, with those treated before age 30 most at risk (Beyer *et al.*, 2013). Major organ toxicity and renal impairment are additional risks of BEP chemotherapy. Survivors may also be at greater risk of further malignancies, particularly sarcomas and leukaemia (Beyer *et al.*, 2013; Fossa, Oldenburg and Dahl, 2009; Haugnes *et al.*, 2012; Horwich, Nicol and Huddart, 2013) as well as lung, gastrointestinal, or urinary cancers (Beyer *et al.*, 2013; Fossa, Oldenburg and Dahl, 2009; Haugnes *et al.*, 2012; Horwich, Nicol and Huddart, 2013). Specifically, testicular cancer survivors have a 1.6-1.8 increased risk of further cancers compared to age matched controls, especially in smokers (Fossa, Oldenburg and Dahl, 2009).

In terms of sexual functioning following orchidectomy, men should be able to function normally with one testicle and have normal levels of libido, however they will be reliant on the remaining testicle for sperm and hormone production (Cancer Research UK, 2014af). Treatment may, however, cause infertility, as cytotoxicity can affect sperm production (Dohle, 2010). A proportion of men may already have a lower sperm count as subfertility is a risk factor for testicular cancer (Groll, Warde and Jewett, 2007; Levine, Fernbach and Stahl, 2013). However, research has demonstrated that the majority of survivors (76%) are able to achieve fatherhood naturally in the 20 years after diagnosis (Brydøy *et al.*, 2005). Treatment may affect men's chances of conceiving naturally, as only 48% of men who received high doses of chemotherapy achieved fatherhood compared to 92% on surveillance (Brydøy *et al.*, 2005; Cancer Research UK, 2015f). Guidelines have recommended that the cryopreservation of semen prior to cancer treatment should be offered to all men (Dohle, 2010;

Williams, 2010). If sperm is collected, artificial reproductive techniques (ARTs) can be undertaken, such as IVF (Dohle, 2010). One study found that 22% of testicular cancer survivors used ARTs (Brydøy *et al.*, 2005). ARTs are necessary for men who have undergone lymph node surgery, as this causes retrograde or dry ejaculation (Cancer Research UK, 2015f). In men with dry ejaculation, only a fifth achieved fatherhood after testicular cancer (Brydøy *et al.*, 2005).

2.2 The psychosocial impact of testicular cancer

While many studies have explored the medical aspects of testicular cancer, there has been a deficit of research exploring the psychosocial issues affecting quality of life (Fleer *et al.*, 2004; Groll, Warde and Jewett, 2007; Luckett *et al.*, 2008). The remainder of part-one of this chapter will provide a narrative review of the literature regarding the psychosocial impact of testicular cancer.

2.2.0 Literature review search strategy

The following databases were systematically searched for relevant articles; PubMed, PsycINFO, Cumulative Index to Nursing and Applied Health Literature (CINAHL), Web of Knowledge, Cochrane Library and Medline as well as 'Grey' literature, including the Electronic Thesis Online Service (EThOS) and Google Scholar. Reference lists of key papers were also searched. Key words used during the literature search were; (*'Testicular cancer', 'Testis cancer')* and *('Psychological', 'Psychosocial', 'Psychosocial oncology')*. Once key topic areas were identified in the literature, specific terms were also used in different combinations to broaden the search, including '*body image', 'sexuality', 'qualitative research', 'fertility', 'work', 'quality of life'* and *'relationships'*. Studies included in the review were restricted to those: 1) available in English, 2) published over the last 20 years (January 1994 to April 2014), and 3) which focused on the psychological and/or social impact of testicular cancer. The search was restricted to the last 20 years as, given the changes that have occurred in testicular cancer treatment over the last few decades, earlier papers on the psychosocial impact may be outdated (Lange and Lin, 2014). Papers were excluded if they focused solely on a) biomedical aspects of testicular cancer b) physical consequences of treatment or late effects (unless these had a psychological element, such as fatigue) c) health behaviours of testicular cancer survivors, d) help seeking or testicular cancer awareness or e) the views of health professionals.

Methodological limitations of the studies were noted when reviewing the papers; however studies that had considerable methodological limitations were not excluded from the review, due to the relative dearth of psychosocial research on testicular cancer. Due to the relative rarity of the disease, many quantitative studies had smaller sample sizes, yet were deemed to yield useful findings, so were included. In total, 75 studies were included, of which the majority were quantitative (n=57), with some qualitative (n=13) and review papers (n=5). Studies identified are synthesised into two areas: 1) quality of life in testicular cancer survivors (HRQoL, psychological functioning, relationships and social functioning, fertility, sexuality and sexual functioning, work and body image) and 2) coping with the psychosocial impact (coping, positive outcomes).

2.2.1 Quality of life in testicular cancer survivors

2.2.1.1 Health related quality of life (HRQoL)

A review from 2004 (Fleer *et al.*) of 23 papers on quality of life after testicular cancer suggested that the majority of men reported a good overall quality of life. Although, the authors acknowledged that the methodological limitations of many of these studies, such as small sample sizes and the use of un-validated questionnaires, meant no firm conclusions could be drawn. More recent studies have also shown that the quality of life of short and long-term survivors was comparable to healthy controls (Bumbasirevic *et al.*, 2013; Fleer *et al.*, 2006a; Fossa, Oldenburg and Dahl, 2009; Joly *et al.*, 2002; Mykletun *et al.*, 2005; Rudberg, Nilsson and Wikblad, 2000). In fact, survivors were found to have even better physical functioning than normal controls (Fleer *et al.*, 2006a; Tuinman *et al.*, 2007). Overall, evidence suggests that the majority of testicular cancer survivors appear to quickly recover and regain their quality of life (Dahl, Mykletun and Fosså, 2005; Fleer *et al.*, 2006a; Fleer *et al.*, 2004; Joly *et al.*, 2002). However, due to the frequent use of the generic SF 36 measure (Ware Jr and Sherbourne, 1992) to assess quality of life, so far, aspects of quality of life which may be specific to testicular cancer, such as body image and sexuality, have not been included (Fosså *et al.*, 2003). In 2003, although one study implemented a testicular cancer module of the European Organisation for Research and

Treatment of Cancer (EORTC) measure; this has not been fully psychometrically validated (Fosså *et al.*, 2003) and only one study has used this to date (Stoehr *et al.*, 2013).

2.2.1.1i Factors associated with overall HRQoL

Longitudinal research has suggested that men's quality of life in terms of physical functioning may be lowered at treatment completion and in the first few months after treatment and then return to normal levels by one year post diagnosis (Tuinman *et al.*, 2007). Two years after chemotherapy, 51% had no change in global HRQoL, 36% had improved and 13% had lower HRQoL since treatment (Fosså *et al.*, 2003). In these patients who all received adjuvant chemotherapy, around a quarter reported ongoing issues with Raynaud's phenomenon, tinnitus or hearing problems at two years post treatment. In most domains of HRQoL, patients reported worse outcomes at three months post chemotherapy, and then improvement after six months (Fosså *et al.*, 2003). One study found that treatment type affected HRQoL, as men who received adjuvant treatment reported poorer HRQoL, including greater pain (Rudberg, Nilsson and Wikblad, 2000). However little evidence for the role of treatment type has been shown elsewhere and some reviews have criticised previous literature for failing to comprehensively explore the role of treatment characteristics (Dahl, Mykletun and Fosså, 2005; Fleer *et al.*, 2004; Mykletun *et al.*, 2005). Key components of a perceived good quality of life were having children, having a job, being fertile and having a partner (Fleer *et al.*, 2006n; Rudberg, Nilsson and Wikblad, 2000).

2.2.1.1ii Fatigue

A commonly reported outcome of chemotherapy for testicular cancer is fatigue with a reported 17-19% of men having persistent post-treatment fatigue (Bumbasirevic *et al.*, 2013; Fosså *et al.*, 2003; Joly *et al.*, 2002; Orre *et al.*, 2008). Fatigue could continue for up to ten years post-treatment and has been associated with poorer quality of life, anxiety and depression, fear of recurrence, somatic problems, neuroticism, older age, lower educational achievement and alcohol problems (Orre *et al.*, 2008; Skaali *et al.*, 2009).

2.2.1.2 Psychological functioning

Being diagnosed and undergoing treatment was found to be the most distressing and stressful period for testicular cancer patients (Kristjanson *et al.*, 2006; Skoogh *et al.*, 2013; Trask *et al.*, 2003; Tuinman *et al.*, 2007). Around two thirds of men wished counselling had been on offer, especially during treatment (Skoogh *et al.*, 2013). However, distress appears to be largely transient as psychological functioning was shown to be comparable to normal populations; although a minority of survivors were at risk of long-term distress (Dahl *et al.*, 2005; Rudberg, Nilsson and Wikblad, 2000; Tuinman *et al.*, 2007). By two years post treatment, 48% of survivors demonstrated improvement in emotional functioning, while 9% deteriorated (Fosså *et al.*, 2003).

2.2.1.2i Depression and suicide

Depression rates amongst testicular cancer survivors (2-18%) have been found to be similar to or even lower than the general population in several large population based studies (Bumbasirevic *et al.*, 2013; Dahl *et al.*, 2005;

Fosså, Dahl and Loge, 2003; Wiechno *et al.*, 2007). Elsewhere, in one US study, depression rates were significantly higher in testicular cancer survivors (17.5%) compared to normative controls (11%) especially in survivors who were smokers, although this may be due to methodological differences (Shinn *et al.*, 2007). Conversely, testicular cancer survivors may have a 20% higher suicide risk than the general population, particularly survivors under 30 years old, shown in two large US population based studies (Alanee and Russo, 2012; Beard *et al.*, 2013).

2.2.1.2ii Anxiety

Testicular cancer survivors have consistently been shown to display higher levels of anxiety than the general population (Dahl *et al.*, 2005; Dahl, Mykletun and Fosså, 2005; Fosså, Dahl and Loge, 2003; Siafaka *et al.*, 2008; Wiechno *et al.*, 2007). In these studies, the incidence of anxiety ranged from 14-28% compared to around 13% in normal populations. Anxiety and stress levels were particularly high amongst younger survivors under 30 years old (Dahl *et al.*, 2005; Dahl, Mykletun and Fosså, 2005; Fosså, Dahl and Loge, 2003; Tuinman *et al.*, 2007). Financial issues, alcohol misuse, sexual problems, unemployment, fatigue, neuropathy, fear of recurrence and previous treatment for mental disorders have also been associated with anxiety (Dahl *et al.*, 2005; Dahl, Mykletun and Fosså, 2005; Fosså, Dahl and Loge, 2003).

2.2.1.2iii Fear of recurrence

In long-term survivors, 19-31% reported they had ‘quite a bit’ and 7-9% ‘very much’ fear of recurrence (Dahl, Mykletun and Fosså, 2005; Pedersen *et al.*, 2012; Skaali *et al.*, 2009). Associations with fear of recurrence included depression, attributions of psychological stress as a cause of the disease (Pedersen *et al.*, 2012), neuroticism, cancer related stress, having an anxiety disorder, fatigue, unemployment, smoking, poorer quality of life and lower self-esteem (Skaali *et al.*, 2009). However, evidence to date has been inconclusive regarding associations with age (Dahl *et al.*, 2005; Pedersen *et al.*, 2012; Skaali *et al.*, 2009). While fear of recurrence was associated with side effects and somatic symptoms, there was no apparent association with treatment type, although these symptoms are associated with chemotherapy (Pedersen *et al.*, 2012; Skaali *et al.*, 2009). As most of the existing studies are cross sectional, it is unknown whether the presence of fear of recurrence is a cause or consequence of psychological morbidity, or whether other non-cancer related events are involved. In a prospective study, while 17% reported worsening anxiety over a recurrence at two years post treatment, 36% reported an improvement (Fosså *et al.*, 2003).

Attending follow-up appointments has shown to be reassuring for men and has not been shown to significantly increase levels of anxiety (MacBride and Whyte, 1999). However, UK men reported several unresolved issues from follow-up appointments surrounding a range of issues including fertility status, contraception, and future duration of appointments (Colbourne, 2005; Colbourne and Sque, 2005). Other qualitative research has indicated post-traumatic stress symptoms, influenced by follow-up appointments and intrusive memories of the event (Jonker-Pool, 2003).

2.2.1.2iv Factors associated with psychological functioning

Survivors who were unemployed, single, childless, had previously experienced more negative life events, or had lower educational achievements, were at higher risk of distress (Fleer *et al.*, 2006n; Fleer *et al.*, 2006x). Younger men (16-25 years) found the post treatment transition more psychologically difficult, and were more likely than older men to express a desire for counselling during this period (Skoogh *et al.*, 2013). Studies have shown that the variance in testicular cancer survivor's distress levels are poorly explained by disease variables (Fleer *et al.*, 2006a; Fleer *et al.*, 2006x; Parker *et al.*, 2003; Skoogh *et al.*, 2013). Survivors with advanced or relapsed testicular cancer have shown similar levels of distress compared to men who only received primary treatment (Dahl *et al.*, 2005; Fleer *et al.*, 2006a; Fleer *et al.*, 2006x). In one study, having a second cancer event was associated with worse mental health in long-term survivors, yet the effect was weak (Fleer *et al.*, 2006n).

Several large scale studies have shown no significant association with psychological morbidity and treatment type (Dahl *et al.*, 2005; Fossa, Moynihan and Serbouti, 1996; Rudberg, Nilsson and Wikblad, 2000; Skaali *et al.*, 2009), although these studies have often focused on long-term survivors (Dahl *et al.*, 2005). Some evidence has suggested that survivors on surveillance following orchidectomy have worse psychological wellbeing and greater anxiety compared to men who receive treatment (Arai *et al.*, 1996; Jones and Payne, 2000), however only small sample sizes were employed. Jones and Payne (2000) generated a grounded theory which explained that patients are '*seekers of safety signals'* elicited from health professionals and other patients to minimise feelings of anxiety and uncertainty. Therefore, having treatment provided more opportunities for men to experience 'safety signals' that accounted for their lower levels of anxiety. Conversely, men on surveillance had to wait for follow-up tests and the passing of time to gain their sense of safety and foreclosure (Jones and Payne, 2000). Elsewhere, a Q sort methodology study revealed that distress appeared to be associated with patient's subjective perceptions of illness, namely the degree that testicular cancer was perceived as a threat (Fleer *et al.*, 2006x).

2.2.1.3 Relationships and social functioning

Testicular cancer has been shown to significantly impact on men's *experience* of sexual and romantic relationships, as well as the *quality* of men's relationships (Carpentier and Fortenberry, 2010; Tuinman *et al.*, 2005). Men's relationship status, especially at the time of diagnosis, has been shown to be an important predictor of psychosocial adjustment (Carpentier and Fortenberry, 2010; Tuinman *et al.*, 2006). Arguably, men in a relationship that precedes the testicular cancer diagnosis have an advantage over those who are single, as well as men who have started a relationship after diagnosis, as having a partner may act as a buffer against cancer-related stress (Carpentier and Fortenberry, 2010; Tuinman *et al.*, 2005; Tuinman *et al.*, 2006). Partners have been shown to be a very important source of support and may help men adjust to testicular cancer (Sheppard and Wylie, 2001). In fact, 62% reported relying on their partner for support, whilst 17% relied on parents, 8% relied on friends and only 0.6% on other cancer patients (Bender *et al.*, 2012). Being single at the time of diagnosis may render men with a certain vulnerability, including greater psychosocial problems, such as poorer mental health, more depressive symptoms, fear of infertility and lower self-esteem, compared to men who are partnered (Fleer *et al.*, 2006a; Tuinman *et al.*, 2010). Younger, single testicular cancer survivors also reported greater concerns over developing future relationships, particularly fears over the issue of disclosing their cancer survivorship status to future romantic partners (Carpentier *et al.*, 2011). One study found that having testicular cancer increased men's marriage rates by 11% compared to healthy populations of single men (Syse, 2008). While divorce rates of survivors have been shown to be comparable to healthy controls (Joly *et al.*, 2002; Rudberg, Nilsson and Wikblad, 2000) and some have reported improvements in their spousal relationship after cancer, a sub sample of men have reported negative relationship changes (Carpentier *et al.*, 2011).

Social functioning was reported to be improved in 41% of men two years following chemotherapy, although 12% reported a deterioration in functioning (Fosså *et al.*, 2003). This may be explained by qualitative research, which highlighted that some men felt supported by their social network, while others discussed a lack of support, which led to a sense of isolation and rejection (Jonker-Pool, 2003). Elsewhere, 'relationships' were one of the most commonly reported unmet need, although it was unclear if men were referring to peer or spousal relationships (Smith *et al.*, 2013a). Furthermore, 17% of testicular cancer survivors expressed a need to talk to others who have experienced cancer (Smith *et al.*, 2013a), although men's preferences regarding the format and timing of peer support was unclear. Men reported that conversations in testicular cancer online forums were psychologically beneficial, allowing them opportunities to negotiate emotional topics and discuss the illness and treatment related decisions (Seymour-Smith, 2013).

2.2.1.4 Work

Research has indicated that testicular cancer survivors are no more likely to be unemployed than men from healthy populations (de Boer *et al.*, 2009; Joly *et al.*, 2002; Rudberg, Nilsson and Wikblad, 2000). One study reported that survivors displayed less ambitious work plans compared to normal controls (Joly *et al.*, 2002), echoing qualitative research which illustrated that men re-evaluated their attitudes towards work and money, and felt relationships were often more important (Brodsky, 1995). It is apparent that being in work is important for testicular cancer survivors, as those who are unemployed are more likely to display poorer psychological functioning (Fleer *et al.*, 2006a; Skaali *et al.*, 2009).

2.2.1.5 Sexuality and sexual functioning

Existing evidence regarding the impact on men's sexual functioning is conflicting. While some evidence suggests that survivors may be more likely to report sexual dysfunction (Dahl *et al.*, 2007; Joly *et al.*, 2002; Kim *et al.*, 2012), others have shown a minimal difference between survivors and controls (Carpentier and Fortenberry, 2010; Incrocci *et al.*, 2002; Tiryaki *et al.*, 2009). Jonker-Pool *et al.*, (2001) observed that higher rates of dysfunction were reported in retrospective studies compared to prospective studies, suggesting that men may overestimate the impact on sexual functioning. Compared to controls, testicular cancer survivors may report more specific problems with decreased libido, erection and ejaculation difficulties following treatment with chemotherapy or radiotherapy (Dahl *et al.*, 2007; Jankowska, 2012; Kim *et al.*, 2012; Nazareth, Lewin and King, 2001). Sexuality-related unmet needs were found in 23-37% of survivors (Bender *et al.*, 2012; Smith *et al.*, 2013a) with one study finding around half of men exhibiting this need, particularly for information on sexual issues during follow-up (Jonker-Pool *et al.*, 2004). Elsewhere, around a fifth of men reported being unable to talk to their partner about their sexual issues (Fegg *et al.*, 2003). However, it is unclear exactly how men would prefer to be supported with this issue, as this topic may be a difficult area to research, as questionnaires were cited as a more limited technique compared to interviewing men on this topic (Brand, Williams and Braybrooke, 2015; Sheppard and Wylie, 2001). Many quantitative studies in this area have employed unstandardized measures, relied on small sample sizes and had low response rates, so the findings should be interpreted with caution (Jankowska, 2012; Nazareth, Lewin and King, 2001). Most have explored sexual functioning rather than looking at sexuality as a whole, including related areas such as intimacy or body image.

2.2.1.5i Masculinity

The threat posed by testicular cancer to the male identity and sense of masculinity has been highlighted previously, mostly by qualitative research (Gurevich *et al.*, 2004). The loss of a testicle may leave some men feeling incomplete and question their own masculinity and male identity (Carpentier *et al.*, 2011; Gurevich *et al.*, 2004). Yet one study demonstrated that these feelings may sometimes run in parallel to also feeling more masculine, as men appeared to feel both less and more masculine after testicular cancer (Gurevich *et al.*, 2004). Elsewhere, in one study, losing a testicle was not felt to affect men's sense of masculinity (Brodsky, 1995). A large quantitative prospective study employing a testicular cancer specific measure, found that the item 'feeling less masculine' had decreased by three months post treatment (Fosså *et al.*, 2003). By two years post treatment, 79% of survivors reported no change in their feelings of masculinity, whilst 10% reported an improvement and 11% deteriorated, which supports the qualitative literature. It has been found that infertility may affect feelings of masculinity, as men may feel inadequate as a partner and fear having to borrow another man's sperm, perceiving it as '*hand me down masculinity'* (p.1602) (Gurevich *et al.*, 2004).

2.2.1.6 Body image

Body image is a concept closely associated with sexuality and masculinity, which may be affected by testicular cancer. To date, there is relatively little research on this topic in men with testicular cancer, particularly for survivors under 30 years old (Carpentier and Fortenberry, 2010) and existing evidence is difficult to interpret. Qualitative studies show that men displayed embarrassment, self-consciousness and worry over losing a testicle, and found the experience emasculating (Gurevich *et al.*, 2004; Kristjanson *et al.*, 2006; Sheppard and Wylie, 2001; Wraith, 2005). Conversely, another qualitative study conducted in the US found that none of the 11 participants were bothered over the loss of their testicle (Brodsky, 1995). Larger studies also show that men felt the same in terms of physical attractiveness, with only 15-20% feeling less attractive, which was associated with lower HRQoL domains, never having fathered children or poorer sexual functioning (Rossen *et al.*, 2012; Rudberg *et al.*, 2002; Rudberg, Nilsson and Wikblad, 2000). Younger and single men more often reported feelings of shame over losing a testicle, compared to older or partnered men (Skoogh *et al.*, 2011) and qualitative research show these men reported feeling like 'damaged goods' (Carpentier *et al.*, 2011). Issues such as hair loss and surgical scars have also been shown to be challenges for younger survivors (Brodsky, 1995; Carpentier *et al.*, 2011). Body image issues may lessen over time and have been shown to return to normal two years post diagnosis (Wraith, 2005). However elsewhere, a significant minority of long-term survivors exhibited body image concerns, as 16% stated they currently missed their testicle or a further 16% had missed it previously (Skoogh *et al.*, 2011). Men with bilateral testicular cancer experienced greater feelings of loss over their testicle (Skoogh *et al.*, 2011). It is, however, unclear whether missing a testicle translated into significant psychological distress or poorer quality of life. Elsewhere, concern over body image was one of the most common unmet needs in Australian male survivors, as around half of men wanted further support to help them adjust to these changes (Bender *et al.*, 2012).

Men may also be given the option of having a testicular prosthesis to replace the missing testicle (Chapple and McPherson, 2004). Men highly valued being offered a prosthetic testicle, and were upset if they had never been offered one (Adshead *et al.*, 2001; Chapple and McPherson, 2004; Skoogh *et al.*, 2011). Reasons for opting for a prosthesis included; body image concerns, a threatened sense of masculinity, the desire to 'look normal' and to hide the loss of a testicle from new sexual partners (Chapple and

McPherson, 2004). The desire for a prosthesis appeared to be regardless of whether men were in romantic relationships (Chapple and McPherson, 2004). In one study, approximately a third of men opted for a prosthesis, of which 27% of these men were dissatisfied with the result (Adshead *et al.*, 2001). Conversely, another study showed that most men are satisfied with the result (Bodiwala, Summerton and Terry, 2007). One small study showed that 68% felt that their body image had improved after receiving a prosthesis, yet 20% reported feeling uncomfortable in intimate relationships (Incrocci, Bosch and Slob, 1999). Men who decided against opting for a prosthesis felt that the loss of testicle would not have a long-term impact on their masculinity, found having one testicle comfortable, felt the scrotal area looked the same, disliked the idea of 'foreign body' and believed their partners weren't bothered about the change (Chapple and McPherson, 2004).

2.2.1.7 Fertility

Testicular cancer survivors were found to be more likely to experience fertility-related distress and *report* problems with fathering children compared to controls, however no differences were found in terms of actually having children (Kim *et al.*, 2010). This was suggested to be due to the possibility of testicular cancer survivors fathering children at a younger age or having more interest in parenting (Kim *et al.*, 2010). Elsewhere, it was shown that while paternity rates amongst men with testicular cancer were high, the process may be prolonged (Brydøy *et al.*, 2005; Carpentier and Fortenberry, 2010). On average, men achieved fatherhood 6.6 years post diagnosis, although this varied depending on the intensity of treatment received (Brydøy *et al.*, 2005). Distress over fertility may be more prevalent in younger men, as well as those treated with chemotherapy or lymph-node dissection surgery (Fleer *et al.*, 2004). Fertility concerns came out as one of the strongest unmet need, although reported by less than 15% (Smith *et al.*, 2013a). It is unclear from the literature how men would want to be supported with this need. Achieving paternity in survivors who desire children has been shown to be highly important in terms of better quality of life and fewer body image concerns than men who are unable to achieve fatherhood (Skoogh *et al.*, 2011; Stoehr *et al.*, 2013).

2.2.2 Coping with the psychosocial impact

2.2.2.1 Coping with testicular cancer

Research into psychological variables relating to adjustment have shown that the majority of survivors (84%) used ‘approach coping’, which involved making active efforts to manage the stressor (Rutskij *et al.*, 2010). Whereas, ‘avoidance coping’, a tendency to be passive towards the stressor, was associated with depression, neuroticism and lower self-esteem (Rutskij *et al.*, 2010). Qualitative work also found that some men actively sought out information while others were passive; and some reached out for support from others, while other men struggled to ask for support (Kristjanson *et al.*, 2006). Men with testicular cancer used coping strategies that included humour, social comparison, maintaining normalcy and repression or boxing away the experience (Chapple and Ziebland, 2004; Colbourne, 2005). Humour helped men manage their feelings, feel ‘normal’, alleviate tension and hide embarrassment in health settings, tell others about their disease and challenge others assumptions about testicular cancer (Chapple and Ziebland, 2004; Ziebland and McPherson, 2006). The personality trait of neuroticism has been associated with psychological and somatic morbidity, suggesting it might be an important variable in adjustment (Grov *et al.*, 2009; Skaali *et al.*, 2009).

2.2.2.2 Positive outcomes

Men may derive positive outcomes from having testicular cancer, as survivors reported better relationships and emotional growth, and 60% felt their outlook on life was more positive since the illness (Fleer *et al.*, 2004; Fleer *et al.*, 2006n). Having a sense of meaning was a key predictor in men's psychological wellbeing, although importantly, meaning making was not related to levels of distress or disease variables (Fleer *et al.*, 2006n). Qualitative data shows that men reported more enjoyment and appreciation of life, had a different perspective and had re-evaluated their priorities after testicular cancer (Brodsky, 1995; Fleer *et al.*, 2006n). Men described feeling more able to deal with adversity, placed a higher value on relationships and felt more intrinsically motivated (Brodsky, 1995). Testicular cancer was also perceived as a transformative 'wake-up call' (Osborne, 2009) and some men reported living more intensely in the 'here and now' (Jonker-Pool, 2003). Conversely, 8% of men in one study felt their outlook on life was more negative, due to anxieties about the future, reduced feelings of control and greater vulnerability (Fleer *et al.*, 2006n).

2.3 Summary and discussion

Testicular cancer survivors have been shown to have comparable levels of quality of life compared to controls (Fleer *et al.*, 2006a; Joly *et al.*, 2002; Rudberg, Nilsson and Wikblad, 2000). It is unclear whether this is due to the use of generic quality of life measures that do not capture the specific experiences of this population, a response shift[1] (Sprangers and Schwartz, 1999), or whether this accurately reflects the way in which men perceive their quality of life after testicular cancer, so this needs to be explored further. Evidence suggests that testicular cancer survivors may be at slightly higher risk of anxiety, sexual dysfunction, infertility and body image concerns, which may affect quality of life (Dahl *et al.*, 2005; Fosså *et al.*, 2003; Rossen *et al.*, 2012). However, existing research on the psychosocial impact of testicular cancer has primarily focused on the physical or sexual impact of the disease, while many other key areas are lacking in understanding, including survivors' illness perceptions, psychological adjustment, body image, coping strategies, support and information needs and relationships (Fleer *et al.*, 2004; Travis *et al.*, 2010). The factors associated with poorer outcomes after testicular cancer are not well understood, as so far, socio-demographic or treatment and disease related variables only explain some of the variance (Fleer *et al.*, 2006a). Further research could explore the psychological variables that might influence successful and quick adjustment to testicular cancer. It is also unclear how positive outcomes that men derive from the disease are related to

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[1] Response shift refers to the shifting perception of what constitutes a good quality of life, in order to accommodate the effects of an illness (Sprangers and Schwartz, 1999).

psychological distress, and how they may play a role in adjusting to the disease.

There is a notable lack of theoretical explanations helping to explain adjustment to testicular cancer (Jones and Payne, 2000) and it is unclear how differing coping styles and strategies might influence adjustment. Few studies have had a prospective design (Brand, Williams and Braybrooke, 2015; Fosså *et al.*, 2003; Rossen *et al.*, 2012; Tuinman *et al.*, 2007; Tuinman *et al.*, 2010) as most have been retrospective, so the direction of causality between variables has been difficult to infer (Carpentier *et al.*, 2011; Jankowska, 2012; Jonker-Pool *et al.*, 2004; Tuinman *et al.*, 2006). Prospective studies may be more useful at exploring the trajectory of adjustment over time.

Few studies have investigated how men experience the transition from treatment to follow-up, which has been explored in other cancer sites (Colbourne, 2005; Jefford *et al.*, 2008; Parry *et al.*, 2011; Simpson and Whyte, 2006). In light of recent policy regarding the re-design of UK follow-up services, exploring men's experiences of adjusting to this transition may inform guidelines regarding post treatment support (Batehup *et al.*, 2012; Department of Heath, Macmillan Cancer Support and NHS Improvement, 2013). The majority of studies have been quantitative, with few previous qualitative research studies in this area, of which many have focused on treatment experiences, or examined specific areas, such as views towards testicular prosthetics (Brodsky, 1999; Carpentier *et al.*, 2011; Chapple and McPherson, 2004; Colbourne, 2005; Colbourne and Sque, 2005; Gascoigne, Mason and Roberts, 1999; Gurevich *et al.*, 2004; Jones and Payne, 2000; Jonker-Pool, 2003; Kristjanson *et al.*, 2006; Osborne, 2009; Seymour-Smith, 2013; Wraith, 2005). Further research needs to examine men's experiences and concerns holistically, taking account of the multiple issues men may face.

Few studies have also been conducted in the UK setting, particularly qualitative work (Chapple and McPherson, 2004; Chapple and Ziebland, 2004; Colbourne, 2005; Moynihan *et al.*, 1998) so cross-cultural differences may account for some of the conflicting findings regarding the effect on sexuality and body image. Further work needs to explore the process of adjustment to body image changes after testicular cancer, as well as how men want to be supported with body image issues. This might inform the development of interventions for the minority of men at risk of body image disturbance. There is also a need for greater exploration of issues including fatherhood, body image and sexuality as a whole, as they may be closely related. Further qualitative research could explore how men with testicular cancer cope with the threat to fatherhood, the strategies they use to manage this, in both single and partnered men. The meaning of fatherhood for men with testicular cancer at different life stages could also be further explored, as well as the impact on men's plans for fatherhood, particularly in younger men.

The impact on work has also received little attention, so more research could examine the meaning of returning to work for men, and men's work and financial-related support needs during treatment and early recovery. Due to the paucity of research, more prospective studies into the variables that might contribute to fatigue are warranted. Future research could also examine the impact on romantic relationships, particularly for younger men, as well as the role of peer support (Carpentier *et al.*, 2011). Further exploration into how men utilise and manage these relationships is needed, particularly regarding emotional disclosure, as well as where and how men seek out different types of support.

Younger men with testicular cancer under 30 years old may be a particularly vulnerable group, at greater risk of anxiety and suicide compared to age matched controls (Alanee and Russo, 2012; Beard *et al.*, 2013; Carpentier and Fortenberry, 2010; Dahl *et al.*, 2005; Fosså, Dahl and Loge, 2003) and have been shown to display greater needs, particularly after treatment completion (Bender *et al.*, 2012; Skoogh *et al.*, 2013; Smith *et al.*, 2013a). Exploration of younger men's experiences during this period is lacking (Carpentier *et al.*, 2011). Evidence also suggests that single men may be more vulnerable, so more research is needed into exploring the issues for these men.

Further exploration is required into how men perceive the threat of a recurrence despite the often excellent prognosis, particularly the role of information given by health professionals. It is not yet clear whether fear of recurrence relates to other cancers or bilateral testicular cancer and how men manage these concerns. Common unmet needs which included fear of recurrence may be correlated with psychological distress and poorer quality of life (Bender *et al.*, 2012; Smith *et al.*, 2013a). However in these studies, the use of a generic unmet needs measure (Hodgkinson *et al.*, 2007) might not have allowed the complexity of men's needs to be explored in depth, so more investigation is warranted into men's support and information needs following treatment. It is also unclear whether men's reporting of unmet needs reflects their willingness to seek out or accept support for these needs, in light of evidence suggesting that men are reluctant to accept help (O'Brien, Hart and Hunt, 2007; O'Brien, Hunt and Hart, 2005). Greater insight is warranted into how testicular cancer survivors utilise different types of professional or lay support available to them.

2.4 Conclusion

Overall, the current state of the literature on testicular cancer survivors is conflicting in many key areas and many noteworthy limitations and gaps exist in the knowledge base. Research is needed to explore how some men may adjust well, whilst a sub group of men might experience psychological morbidity, anxiety, fertility and body image issues. In order to usefully inform interventions, further studies that elicit the psychological variables associated with adjustment and recovery are needed. In particular, men's preferences for support and the process of adjustment to the psychosocial impact of testicular cancer need particular attention. Qualitative methodologies might be useful at providing a more detailed insight into experiences of testicular cancer survivors. The use of prospective designs might highlight the role for interventions at different points along the cancer journey. This thesis will explore these issues in order to improve understanding of men's experiences and how survivors can be better supported.

Chapter 3: A Literature Review of the Psychosocial Impact of Hodgkin Lymphoma

3.1 Background

3.1.1 Incidence and risk factors

Each year, around 1,800 people in the UK are diagnosed with Hodgkin lymphoma, a type of white blood cell cancer which develops in the lymph nodes (Cancer Research UK, 2014n). Males are at slightly higher risk than females (57% and 43% of cases respectively) (Cancer Research UK, 2014g). In the UK, the incidence rate of Hodgkin lymphoma is 2.7-2.8 per 100,000 people and this rate is increasing (Cancer Research UK, 2014g; Townsend and Linch, 2012). Hodgkin lymphoma has bimodal incidence peaks, affecting individuals at both ends of the lifespan, particularly younger adults in their 20's and adults over 65 years old (Baxi and Matasar, 2010; Cancer Research UK, 2014g). Currently, Hodgkin lymphoma is the 3rd most common cancer found in younger adults aged 15-29 years old (Cancer Research UK, 2014g).

Hodgkin lymphoma is characterised by the presence of clonal malignant Hodgkin and Reed-Sternberg (HRS) cells, which have a B cell origin in most cases (Küppers and Hansmann, 2005). There are two broad types of Hodgkin lymphoma; around 60% are classical Hodgkin lymphoma, 10% are nodular lymphocyte-predominant Hodgkin lymphoma, and the remaining 30% are unspecified types of Hodgkin lymphoma (Cancer Research UK, 2014g; Gobbi *et al.*, 2013). Classical Hodgkin lymphoma has four subtypes; nodular sclerosis, mixed cellularity, lymphocyte depletion, and lymphocyte-rich Hodgkin lymphoma (Gobbi *et al.*, 2013; Jaffe, 2009).

Currently, there are several known risk factors for Hodgkin lymphoma; infection with Epstein Barr virus (around 45% of diagnoses); human immunodeficiency virus (11% increased risk); having an organ transplant (2-4% higher); auto-immune disease (2-10% higher depending on disease); non-Hodgkin lymphoma (7% higher); a first degree relative with Hodgkin lymphoma (3% higher); being overweight (41% higher); or a smoker (10-15% higher) (Cancer Research UK, 2014f; Gobbi *et al.*, 2013).

3.1.2 Symptoms and diagnosis

Hodgkin lymphoma patients will often present with one or multiple painless swellings in the neck, groin, thoracic or axillary area (Cancer Research UK, 2014u). Around two thirds of patients will present with enlarged lymph nodes in their neck (Cancer Research UK, 2014a). Hodgkin lymphoma can also be found in the spleen, liver, lung or bone (Cancer Research UK, 2014a). A quarter of patients will present with 'B symptoms' which include a fever, drenching night sweats or at least 10% weight loss (Townsend and Linch, 2012). Other symptoms may include fatigue as well as pain or itching (pruritis) after drinking alcohol (Townsend and Linch, 2012). If lungs are affected, patients may report dyspnoea (difficulty breathing) or coughing (Cancer Research UK, 2014a). In rare cases, the disease may be found in testicular or gastrointestinal tissues (Gobbi *et al.*, 2013). There is currently no screening program for Hodgkin lymphoma due to the relative rarity of the disease (Cancer Research UK, 2014a).

Following diagnosis by disease subtype, Hodgkin lymphoma is classified into one of four stages, which are based on the number of affected areas and the location of the disease in the body (Gobbi *et al.*, 2013). The stages are as follows: stage I (disease present in one lymph node), stage II (disease present in two lymph nodes or an organ plus one lymph node), stage III (lymph nodes on both side of diaphragm affected) or stage IV (disease spread to many lymph nodes and organs) (Diehl, Thomas and Re, 2004). Around 55% of patients will present at either stages I (24%) or II (31%), with 15% at stage III and 13% at stage IV, with the remainder 'not known' (Cancer Research UK, 2014g). Early stage disease (stage I or II) is often classified as either favourable or unfavourable, depending on risk factors such as B symptoms or disease bulk (Townsend and Linch, 2012). Unfavourable early stage disease is an intermediate stage between early and advanced stage lymphoma (Gobbi *et al.*, 2013).

3.1.3 Treatment

Treatment regimens have been constantly evolving over the last few decades (Diehl, Thomas and Re, 2004). Until a few decades ago, radiotherapy was used to treat early stage disease, however due to a high rate of relapse and risk of late effects, combined chemotherapy with smaller doses of radiotherapy are now administered (Diehl, Thomas and Re, 2004; Gobbi *et al.*, 2013). Typically doxorubicin (that was previously named adriamycin), bleomycin, vinblastine, and dacarbazine (ABVD) is administered as first-line chemotherapy (Ng and Mauch, 2009; NICE, 2003). Other more intensive chemotherapy regimens such as bleomycin, etoposide, doxorubicin, cyclophosphamide, vincristine, procarbazine, and prednisone (BEACOPP), which contains an additional topoisomerase II inhibitor, alkylating agent and a high-dose steroid, may be given instead of ABVD or in combination with it for patients with unfavourable risk factors (Flowers and Armitage, 2010). Radiotherapy may also be administered in combination with chemotherapy (Diehl, Thomas and Re, 2004; NICE, 2003). Treatments may have a range of side effects, including nausea, diarrhoea, mouth ulcers, alopecia and fatigue (Cunningham, 2006). Steroids given alongside chemotherapy often cause increased appetite, agitation, hyperactivity and insomnia (McGrath *et al.*, 2007).

Treatment varies according to staging. Patients with favourable early stage disease often receive two cycles of ABVD chemotherapy, usually with a short dose of radiotherapy (Townsend and Linch, 2012) and patients with early stage unfavourable disease may receive 4-6 cycles of ABVD (Townsend and Linch, 2012). The 'gold standard' treatment for advanced disease is often considered to be ABVD chemotherapy with or without radiotherapy, although BEACOPP regimen has also been shown to be efficacious (Diehl, Thomas and Re, 2004; Townsend and Linch, 2012). Following treatment completion, patients are usually followed-up in clinic every 3-4 months for 2 years, then every 6 months for another 3 years (Gobbi *et al.*, 2013). The majority of patients will stay in remission, however some will relapse (10-30%) or have refractory disease (5-10%), in which the disease progresses or fails to respond to treatment within 90 days of treatment completion (Ansell, 2012; Townsend and Linch, 2012). Relapsed or refractory disease is more common in patients with advanced disease (20-30%) compared to early stage disease (10%) (Townsend and Linch, 2012). These patients may require salvage chemotherapy, sometimes including localised radiotherapy, as well as autologous stem cell transplant (using the individual's own stem cells harvested prior to high-dose chemotherapy and transfused post high-dose chemotherapy) (Ansell, 2012).

3.1.4 Survival

Survival rates for Hodgkin lymphoma have improved markedly over the last 40 years and the overall prognosis is excellent, due to faster diagnoses and successful improvements to treatment regimens (Eichenauer and Engert, 2012; Flowers and Armitage, 2010; Townsend and Linch, 2012). Hodgkin lymphoma is the third most curable cancer (behind testicular cancer and non-metastatic malignant melanomas), as over 80% of patients (82% and 84% for men and women respectively) will survive for at least 5 years (Cancer Research UK, 2014p; Office for National Statistics, 2011). In line with other cancer sites, survival chances are highest amongst younger adults with Hodgkin lymphoma, as 5 year survival currently lies at 93% for 15-39 year olds (Cancer Research UK, 2014p). Around two thirds of all deaths from Hodgkin lymphoma are in patients over 60 years old (Cancer Research UK, 2014e). The presence of B symptoms or bulky disease have been shown to adversely affect survival rates (Townsend and Linch, 2012). In patients with early stage disease, over 90% will expect to survive, whereas between 75-90% of advanced stage patients will survive (Townsend and Linch, 2012). For patients who relapse, survival is highly dependent on the timing of relapse, with only around a quarter of patients with refractory disease surviving for 5 years, and 46% if relapse is between 3-12 months following initial treatment completion (Josting *et al.*, 2000; Townsend and Linch, 2012).

3.1.5 Long-term physical morbidity

Although Hodgkin lymphoma has become more curable, survivors may face a variety of late effects due to the toxicity of treatment regimens (Gobbi *et al.*, 2013). Minor toxic effects of treatment may involve endocrine dysfunction, long-term immunosuppression and viral infections (Diehl, Thomas and Re, 2004). More serious long-term effects may include cardiac and pulmonary toxicity, sterility, fatigue, osteoporosis, or secondary malignancies (Diehl, Thomas and Re, 2004; Ng and Mauch, 2009; NICE, 2003; Roper, 2009). The most common causes of death in long-term (<15 years) Hodgkin lymphoma survivors are a second primary malignancy, followed by cardiovascular morbidity (Baxi and Matasar, 2010; Ng and Mauch, 2009). For Hodgkin lymphoma survivors, the risk of developing a second malignancy is 18% (men) and 26% (women), compared to 7% (men) and 9% (women) in the general population (Hodgson *et al.*, 2007a). Survivors are at risk of leukaemia, non-Hodgkin lymphoma and solid tumours, such as breast and lung cancer, which account for the majority of second primary tumours (Baxi and Matasar, 2010; Ng and Mauch, 2009; Swerdlow *et al.*, 2011). Young female survivors are at greatest risk of breast cancer, which is most likely to occur 15 years or more after Hodgkin lymphoma, suggesting the need for early screening (Ibrahim *et al.*, 2012). The risk of second cancers has been related to treatment with radiotherapy in younger women, smoking and treatment with alkylating chemotherapy, such as the BEACOPP regime (Diehl, Thomas and Re, 2004; Ng and Mauch, 2009). Undergoing an autologous stem-cell transplant also carries risks, such as graft-versus-disease effects and transplant-related mortality (Townsend and Linch, 2012). These patients are at higher risk of death from secondary malignancies, due to use of high-dose chemotherapy, than patients treated with conventional treatment (Goodman *et al.*, 2008).

Sterility may also occur in men and women due to the use of alkylating agents, and is more likely with BEACOPP as opposed to ABVD (Gobbi *et al.*, 2013) due to the additional use of cyclophosphamide. BEACOPP has been found to be associated with increased risk of premature ovarian failure and azoospermia (lack of sperm found in the semen), when compared to the ABVD regimen (Harel, Fermé and Poirot, 2011). Patients who underwent radiotherapy only or low gonadotoxic chemotherapy are most likely to conceive, whilst higher doses of alkylating chemotherapy pose the greatest risk to fertility (Harel, Fermé and Poirot, 2011; Kiserud *et al.*, 2007). There is also a higher risk of ovarian failure in women diagnosed at age 30 years or above (Harel, Fermé and Poirot, 2011; Kiserud *et al.*, 2007). In women under 30, alkylating chemotherapy may cause premature ovarian failure in around 5-25% of survivors, and cause prolonged azoospermia in 90-100% of men (Harel, Fermé and Poirot, 2011). Therefore, ARTs such as sperm and embryo cryopreservation may be offered.

3.2 The psychosocial impact of Hodgkin lymphoma

In addition to physical late effects, it is important to examine the psychosocial impact that a diagnosis and treatment for Hodgkin lymphoma may have during survivorship. The remainder of this chapter will provide a narrative review of the literature regarding the psychosocial impact of Hodgkin lymphoma on survivors.

3.2.1 Literature review search strategy

The following databases were systematically searched for relevant articles; PubMed, PsycINFO, Cumulative Index to Nursing and Applied Health Literature (CINAHL), Web of Knowledge, Cochrane Library and Medline, as well as 'Grey' literature, including the Electronic Thesis Online Service (EThOS) and Google Scholar. Reference lists of key papers were also searched. Key words used during the literature search were; ('*Hodgkin's disease'* OR '*Hodgkin lymphoma'* OR '*Hodgkin's lymphoma')* AND *('Psychological'* OR *'Psychosocial'* OR *'Psychosocial oncology')*. Once key topic areas were identified in the literature, specific terms were also used in different combinations to broaden the search, including '*body image', 'sexuality', 'qualitative research', 'fertility', 'work', 'quality of life'* and *'relationships'*. The inclusion criteria were as follows; studies which were 1) available in English, 2) published over the last 20 years (January 1994 to April 2014), and 3) focused on the psychological and/or social impact of Hodgkin lymphoma. Papers were excluded from the literature review if they focused solely on a) biomedical aspects of Hodgkin lymphoma b) physical consequences of treatment or late effects (unless these had a psychological element, such as fatigue) c) health behaviours of Hodgkin lymphoma survivors or help seeking e) mixed groups of lymphoma or haematological survivors f) the views of health professionals treating patients with Hodgkin lymphoma or g) survivors of childhood or adolescent Hodgkin lymphoma (diagnosed before age 18). In total 42 studies were found and included in the review.

Methodological limitations of the studies were considered when reviewing the papers; however studies that had considerable methodological limitations were not excluded from the review due to the relative dearth of research on psychosocial aspects of Hodgkin lymphoma. The studies and the literature as a whole have been critiqued in light of their methodological considerations, and the implications this has for future research. Studies identified have been synthesised into two key areas; 1) *quality of life* (physical, role, social and global functioning, fatigue, fertility concerns, work and financial issues, interpersonal and sexual issues, psychological and emotional functioning) and 2) *perceptions of late effects of treatment and positive outcomes* (perceptions of breast cancer risk and positive psychological consequences).

3.2.2 Quality of life in Hodgkin lymphoma survivors

The majority of papers on the psychosocial impact of Hodgkin lymphoma have examined health-related quality of life (HR-QoL) using a variety of different measures.

3.2.2.1 Physical quality of life, cognitive and role functioning

Hodgkin lymphoma survivors may be more likely to report impairments in physical functioning compared to the general population or controls (Abrahamsen *et al.*, 1998; Brandt *et al.*, 2010; Gil-Fernández *et al.*, 2003; Joly *et al.*, 1996; Loge *et al.*, 1999f; Mols *et al.*, 2006; van Tulder, Aaronson and Bruning, 1994). Around twice as many survivors (19%) were physically disabled compared to the normal population (Abrahamsen *et al.*, 1998). Greater impairments in cognitive functioning in survivors (13%) were also found in comparison to controls (2%) (Brandt *et al.*, 2010; Joly *et al.*, 1996). Survivors were also more likely to report impairments in role functioning (Joly *et al.*, 1996; van Tulder, Aaronson and Bruning, 1994) and have issues with strenuous activities, due to breathlessness (Gil-Fernández *et al.*, 2003).

3.2.2.1i Factors associated with physical quality of life

Younger survivors were more likely to report better physical functioning and less severe symptoms, compared to those over 60 years old (Heutte *et al.*, 2009; Loge *et al.*, 1999f). Men also reported better physical functioning than women (Heutte *et al.*, 2009; Loge *et al.*, 1999f). The number of recurrences (Goodman *et al.*, 2008) or disease stages IB and IIB (Loge *et al.*, 1999f) were associated with worse physical functioning. When compared to survivors treated with conventional chemotherapy, patients receiving high dose chemotherapy followed by stem cell transplantation showed comparable levels of physical functioning, apart from greater dyspnoea (Brandt *et al.*, 2010).

3.2.2.2 Fatigue

Fatigue levels in Hodgkin lymphoma samples were found to be higher than normal populations in many studies (Brandt *et al.*, 2010; Daniels *et al.*, 2014; Daniels *et al.*, 2013; Ganz *et al.*, 2003; Hjermstad *et al.*, 2005; Hjermstad *et al.*, 2006; Joly *et al.*, 1996; Loge *et al.*, 1999a; Wettergren *et al.*, 2003). Systematic review evidence indicates that the prevalence of fatigue may vary substantially between studies (11-76%) (Daniels *et al.*, 2013). Five out of 22 of these studies, however, related to the same cohort of survivors in Norway for which the prevalence rate of fatigue was 26-30% (Knobel *et al.*, 2001; Loge *et al.*, 1997; Loge *et al.*, 1999a; Loge *et al.*, 1999f; Loge *et al.*, 2000).

3.2.2.2i Factors associated with fatigue

Fatigue was found to be higher in older survivors, particularly those over 60 years old, which may be influenced by the normal ageing process (Daniels *et al.*, 2013; Heutte *et al.*, 2009; Hjermstad *et al.*, 2005; Loge *et al.*, 2000). Daniels *et al.,* (2013) concluded that there is almost no evidence that treatment modality and stage of initial disease is associated with fatigue. Combined treatment was associated with greater fatigue at 6 months post treatment, but not in the long-term (Ganz *et al.*, 2003; Hjermstad *et al.*, 2005). Fatigue was not associated with gender in one study (Miltenyi *et al.*, 2010), although elsewhere, female survivors reported more fatigue (Daniels *et al.*, 2013; Heutte *et al.*, 2009). The majority of studies found no significant association between having a relapse and fatigue (Daniels *et al.*, 2013; Miltenyi *et al.*, 2010), with one study showing an association (Rüffer *et al.*, 2003). Fatigue was, however, found to be related to the presence of late effects, namely pulmonary dysfunction (Knobel *et al.*, 2001; Miltenyi *et al.*, 2010). The presence of B symptoms at diagnosis has also been associated with higher levels of fatigue (Heutte *et al.*, 2009; Hjermstad *et al.*, 2005), although this association was not found elsewhere (Miltenyi *et al.*, 2010). One large prospective study found that fatigue at the end of treatment was the only predictor of persistent fatigue (Heutte *et al.*, 2009). Patients treated before 1980 were found to have higher levels of chronic fatigue (Hjermstad *et al.*, 2005).

Daniels *et al.*, (2013) noted that most previous studies are cross-sectional, so it is difficult to infer causality, and only two studies had employed prospective, longitudinal designs (Ganz *et al.*, 2003; Heutte *et al.*, 2009). Some evidence is also drawn from samples that were treated pre-1980's, so regimens have changed in this time and findings may not relate to current survivors (Loge *et al.*, 1999a). While the evidence for socio-demographic, treatment and disease variables in determining levels of fatigue is contradictory and weak (Daniels *et al.*, 2013), there is some evidence that psychological factors may influence fatigue (Daniels *et al.*, 2014; Loge *et al.*, 2000). Varying degrees of correlation have been shown as anxiety and depression was found to be moderately (Loge *et al.*, 2000) and strongly (Daniels *et al.*, 2014) associated with fatigue. Other psychological factors such as social support, particularly emotional and informational support, were found to be associated with less fatigue (Soares *et al.*, 2013), although this study used a cross-sectional design.

3.2.2.3 Social functioning and social support

Only one study has specifically explored social functioning in Hodgkin lymphoma survivors (Soares *et al.*, 2013), although several studies have examined social impairment as a multidimensional component of HRQoL. Several studies have indicated that survivors have poorer social functioning compared to controls (Brandt *et al.*, 2010; Gil-Fernández *et al.*, 2003; Loge *et al.*, 1999f; Mols *et al.*, 2006). Having a social network and social support has been associated with better physical and mental quality of life in long-term Hodgkin lymphoma survivors, although the effect was small (Soares *et al.*, 2013). Due to the cross-sectional nature of this study, it was unclear whether those who had a better quality of life were more able to maintain social support. Survivors who were 10-15 years post treatment were shown to have better social functioning than those 5-9 years post treatment (Mols *et al.*, 2006).

3.2.2.4 Work and financial issues

Some evidence shows that survivors reported more limitations at work (van Tulder, Aaronson and Bruning, 1994), although elsewhere, no differences were found between survivors and controls (Mols *et al.*, 2006; Wettergren *et al.*, 2003). Survivors did, however, report having less ambitious work plans compared to controls (Abrahamsen *et al.*, 1998; Joly *et al.*, 1996) and around a third had changed their educational (e.g. going to university) or work plans due to the disease (Abrahamsen *et al.*, 1998). Elsewhere, 18% of survivors felt treatment for the disease affected their career, and 11% stated that treatment affected full-time work (Ford *et al.*, 2008). It is unclear from these studies whether survivors viewed these changes as positive or negative. Around one year after treatment, 82% of survivors had returned to either full or part-time work, suggesting that the effect of Hodgkin lymphoma on employment was largely transient (Abrahamsen *et al.*, 1998). Many studies have indicated that survivors were more likely than controls to report financial difficulties such as borrowing money from banks (Brandt *et al.*, 2010; Gil-Fernández *et al.*, 2003; Joly *et al.*, 1996; Wettergren *et al.*, 2003). Over half of younger adult survivors were using financial support services around the time of treatment completion (Roper *et al.*, 2013).

3.2.2.5 Interpersonal and sexual issues

3.2.2.5i Relationships

Very few studies have explored the impact of Hodgkin lymphoma on romantic relationships. The studies that have examined this area were published before 1994, and are outside the scope of this review. Two studies that investigated whether survivors were more or less likely to experience marital breakdown compared to a control group showed inconclusive results (Abrahamsen *et al.*, 1998; Joly *et al.*, 1996). Elsewhere, survivors reported less frequent changes to their relationships with peers compared to controls (Joly *et al.*, 1996). One unpublished qualitative study found that young survivors felt that some of their relationships with others were strengthened, whilst other relationships were strained and did not endure, which was attributed to having cancer (O'Dell, 2010).

3.2.2.5ii Sexual functioning

Findings regarding the impact on sexual functioning are conflicting across studies. Some evidence suggests that the majority of survivors had no persistent impairment and only a minority (13%) reported ongoing sexual issues (Abrahamsen *et al.*, 1998; Behringer *et al.*, 2013). Of those with sexual issues, the most frequently reported were a reduced interest in sex, premature menopause or erectile dysfunction (Abrahamsen *et al.*, 1998). Overall, levels of sexual satisfaction in long-term survivors were found to be comparable to controls (Eeltink *et al.*, 2013; Recklitis *et al.*, 2010). Although poorer satisfaction was found in survivors in one study, this may be influenced by outdated treatment regimens (van Tulder, Aaronson and Bruning, 1994). Males or younger survivors had better sexual functioning than females or those over 50 years old (Behringer *et al.*, 2013; Heutte *et al.*, 2009). Survivors treated with ABVD or with early stage disease reported better sexual functioning than advanced stage patients (Behringer *et al.*, 2013).

3.2.2.6 Fertility and parenthood concerns

Very few studies have examined the impact of Hodgkin lymphoma treatment on fertility and parenthood outside of the medical domain (Hodgson *et al.*, 2007b; Kiserud *et al.*, 2007; van der Kaaij *et al.*, 2012). Post treatment parenthood was achieved by 70-76% of Hodgkin lymphoma survivors (Hodgson *et al.*, 2007b; van der Kaaij *et al.*, 2012). Findings are inconclusive whether women differed from controls in terms of pregnancy rates (Hodgson *et al.*, 2007b; van der Kaaij *et al.*, 2012). Amongst survivors who had children already before treatment, only 12% of these had more children compared to 22% of controls (van der Kaaij *et al.*, 2012). Reasons for not having children after Hodgkin lymphoma included; feeling the family was completed already, being single (van der Kaaij *et al.*, 2012), assumptions over infertility after treatment or lack of awareness over fertility status (Eeltink *et al.*, 2013; Kiserud *et al.*, 2007).

3.2.2.7 Psychological functioning

Over the last 20 years, only 3 cross-sectional studies have specifically examined psychological issues in Hodgkin lymphoma survivors directly (Loge *et al.*, 1997; Norum and Wist, 1996a; Varela *et al.*, 2013). Other studies have examined mental or emotional functioning as a component of HRQoL, rather than measuring the presence of psychological distress. Only two studies have employed a prospective design (Heutte *et al.*, 2009; Roper *et al.*, 2013). The majority of the evidence indicates that levels of psychological HRQoL in survivors are comparable to controls (Gil-Fernández *et al.*, 2003; Joly *et al.*, 1996; Loge *et al.*, 1999a; van Tulder, Aaronson and Bruning, 1994; Wettergren *et al.*, 2003; Wettergren *et al.*, 2004) with only one study finding that survivors reported worse emotional functioning (Brandt *et al.*, 2010). However, higher numbers of anxiety cases (15%) were found amongst Hodgkin lymphoma survivors compared to the general population in Norway (Loge *et al.*, 1997), which was echoed in a US study that showed similar levels of anxiety caseness (16%) in survivors (Ford *et al.*, 2008). Levels of depression (4%) did not differ from the population norm (Loge *et al.*, 1997).

3.2.2.7i Factors associated with psychological functioning

Evidence for the role of socio-demographic and treatment variables in psychological distress is conflicting (Roper, 2009). Previous studies have shown no clear associations between gender and levels of anxiety (Loge *et al.*, 1997; Norum and Wist, 1996a). Survivors who are married displayed less distress compared to separated or divorced survivors (Loge *et al.*, 1997). Treatment type or disease stage were unrelated to distress, however receiving a combined treatment modality predicted clinical levels of anxiety (Loge *et al.*, 1997) and was associated with more symptom distress at 6 months (Heutte *et al.*, 2009). Poorer emotional functioning was associated with the presence of late complications (Miltenyi *et al.*, 2010). Having a 'sense of coherence'[2] was strongly associated with better mental health in survivors as well as controls (Wettergren *et al.*, 2004). Findings are conflicting regarding the association between age and psychological distress (Ford *et al.*, 2008; Heutte *et al.*, 2009; Loge *et al.*, 1997; Loge *et al.*, 2000). In a small study of younger adult survivors, 50% displayed emotional distress at treatment completion and a quarter were using emotional support services, such as peer or professional counselling (Roper *et al.*, 2013). Distress levels in younger adults declined significantly to 11% at 6 months post treatment (Roper *et al.*, 2013). Other studies have shown no clear association between distress levels and time since treatment, with conflicting findings to date (Loge *et al.*, 1997; Mols *et al.*, 2006).

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[2] Sense of coherence refers to an individual's perceptions of the manageability, meaningfulness and comprehensibility of the illness (Antonovsky, 1987)

3.2.2.7ii Post-traumatic stress

Long-term survivors (7-34 years post diagnosis) were not found to differ significantly from sibling controls in terms of PTSD (Varela *et al.*, 2013). However 35% fulfilled partial criteria for PTSD, which was significantly higher than the rate in controls (18%) (Varela *et al.*, 2013). In survivors with partial PTSD, 87% experienced functional impairment. Around half of survivors deemed previous traumas more bothersome than Hodgkin lymphoma, suggesting past traumas may have contributed to this finding and 12% didn't perceive the experience of Hodgkin lymphoma as a traumatic event (Varela *et al.*, 2013).

3.2.2.7iii Fear of recurrence

Thoughts and worries about disease was one of the most common areas of concern amongst survivors (Wettergren *et al.*, 2003). In long-term survivors, 20 years on average post treatment, over 80% reported high fears of recurrence of Hodgkin lymphoma and of secondary cancers (Ford *et al.*, 2008). Qualitative research showed that female survivors discussed fears of recurrence, particularly after having children (Bober *et al.*, 2007). Younger adults survivors were shown to grapple with fears of mortality and uncertainty and displayed a compromised trust in the future, as having cancer at a young age was unexpected and challenged their assumptions about life (Gibbs, 2002; O'Dell, 2010).

3.2.2.8 Perceptions of global health status

Hodgkin lymphoma survivors have reported comparable global health status compared to controls, although simultaneously reported more difficulties in specific health domains, such as physical functioning (Gil-Fernández *et al.*, 2003; Heutte *et al.*, 2009; Joly *et al.*, 1996; Wettergren *et al.*, 2003; Wettergren *et al.*, 2004). In contrast, other studies have found that survivors report lower general health compared to controls (Loge *et al.*, 1999f; Mols *et al.*, 2006; van Tulder, Aaronson and Bruning, 1994). These contrasting findings may be due to the different measures of HRQoL used by studies, as some are cancer specific and others are not. Better global HR-QoL has been reported in younger survivors, especially males (Heutte *et al.*, 2009; Norum and Wist, 1996c; Oerlemans *et al.*, 2011). Treatment type has not been found to be associated with global HRQoL in some studies (Heutte *et al.*, 2009; Loge *et al.*, 1999f; Mols *et al.*, 2006; Wettergren *et al.*, 2004), while other research found an association during the first year post treatment only (Ganz *et al.*, 2003; Greil *et al.*, 1999). Disease variables had little association with global HRQoL (Wettergren *et al.*, 2003) such as having a relapse (Loge *et al.*, 1999f) or undergoing stem cell transplants, and these survivors showed comparable global HRQoL to the general population, despite being at increased risk of mortality and symptoms (Goodman *et al.*, 2008; Minn *et al.*, 2012).

3.3.3 Perceptions of late effects of treatment and positive outcomes

3.3.3.1 Perceptions of breast cancer risk

Qualitative studies exploring perceptions surrounding risk of late effects have found that female Hodgkin lymphoma survivors often underestimated or knew very little about the risk of developing breast cancer (Bober *et al.*, 2007; Grinyer, 2010). A UK study found that only 10% of female survivors recalled being told about their risk of breast cancer, whilst others recalled very inaccurate information or demonstrated poor understanding of the risk (Absolom *et al.*, 2007). This suggests that more information and support should be available to alert women to this risk. Yet Bober *et al.,* (2007) illustrated the complexities of attending breast cancer screening, as while some women felt screening was reassuring, a few participants described their worry as 'constant' over cancer. This suggests that performing breast self-examination or having a mammogram could be a trigger for anxiety, and screening conflicted with the desire to 'feel normal' and place the cancer experience in the past. Many coped with these fears through avoidance or distraction strategies, with only a minority finding that contact with health professionals was helpful at reducing fears (Bober *et al.*, 2007). Overall, some appeared fatalistic over having cancer again, feeling they had little control over this risk, which led the authors to conclude that education for survivors should be placed in "*a health promoting context rather than a disease detection framework*" (p.45) to reduce anxiety (Bober *et al.*, 2007). Elsewhere, it was found that women who were recalled for screening displayed minimal distress over hearing about their risk of breast cancer and most were keen to undergo screening (Absolom *et al.*, 2007). Subsequently, the majority (76%) were reassured over their health (Absolom *et al.*, 2007). Overall, although the literature is small, research to date suggests that female survivors are ill-prepared for the potential late effects of treatment.

3.3.3.2 Positive psychological consequences

Several studies have highlighted the potential positive psychological changes that may exist following Hodgkin lymphoma. One study found that around two thirds of survivors reported that their view on life and themselves had changed for the better (Wettergren *et al.*, 2003). Survivors also discussed how they ‘cherished the now’ following Hodgkin lymphoma and had a new perspective on life (O'Dell, 2010). These positive outcomes were preceded by the struggles encountered with change and loss.

3.3 Summary and discussion

The psychosocial impact on Hodgkin lymphoma survivors is a distinctly under-researched area, in comparison to other cancer sites (Thompson and Mills, 2010), as only 42 articles were identified in the last 20 years, of which only half were in the last decade. Hodgkin lymphoma survivors may be at increased risk of various psychosocial issues during survivorship, particularly difficulties with physical and role functioning, fatigue, anxiety and fear of recurrence, social impairment, financial difficulties, and fertility and sexual issues (Daniels *et al.*, 2013; Heutte *et al.*, 2009; Loge *et al.*, 1997; Roper, 2009). For some of these issues, the impact appears transient as many studies on long-term survivors find comparable levels of quality of life in survivors compared to the normal population (Heutte *et al.*, 2009; Joly *et al.*, 1996; Oerlemans *et al.*, 2011; Wettergren *et al.*, 2003). This would suggest that survivors have found ways of coping with Hodgkin lymphoma; however the processes involved in positive adjustment are unclear from the extant literature. As the majority of existing studies have explored the issues in long-term survivors, the literature on early survivorship is sparse, particularly regarding the psychological impact.

Existing research can also be criticised on methodological grounds, as studies are mostly cross-sectional, retrospective and conducted at single sites (Baxi and Matasar, 2010). Cross-sectional designs do not allow for causal determinants of quality of life to be explored. Retrospective studies may be affected by recall bias in participants due to the passing of time, and single site studies may lack generalisability. In this review, only 6 studies were identified which employed longitudinal designs (Behringer *et al.*, 2013; Ganz *et al.*, 2003; Heutte *et al.*, 2009; Hjermstad *et al.*, 2005; Khimani *et al.*, 2013; Roper *et al.*, 2013). The majority of the literature to date has used quantitative questionnaires with very few qualitative studies (Bober *et al.*, 2007; Gibbs, 2002; Grinyer, 2010; O'Dell, 2010) of which two are unpublished theses (Gibbs, 2002; O'Dell, 2010). Very few studies have used theoretical frameworks for designing their studies and interpreting the findings (Cameron *et al.*, 2001; Gibbs, 2002; Roper *et al.*, 2013; Wettergren *et al.*, 2004). Studies have also measured HRQoL using a variety of different measures, so it is difficult to compare findings across studies. The EORTC QLQ C30 measure has been commonly used by many studies (Daniels *et al.*, 2014; Gil-Fernández *et al.*, 2003; Heutte *et al.*, 2009; Joly *et al.*, 1996), which is a quality of life questionnaire specific to cancer. A Hodgkin lymphoma specific module of this measure is currently in development so has not yet been utilised.

There are also few studies which have specifically explored younger adults with this cancer, as research studies have predominately incorporated the wide age spectrum of the disease. Although younger adult survivors appear at less risk of physical impairments such as fatigue and sexual dysfunction compared to older adults, a significant minority of younger adults may experience distress and seek out psychological support services (Ford *et al.*, 2008; Roper *et al.*, 2013). Issues such as late effects, infertility and parenthood may be more relevant to younger adult survivors due to their life stage, so more research on younger survivors is warranted. There is also a lack of research examining quality of life in survivors who have undergone treatment for relapsed or refractory lymphoma, although the evidence so far shows that these patients have comparable levels of quality of life to survivors who received initial treatment (Brandt *et al.*, 2010). The majority of studies have also been conducted outside of the UK, often in Norway, the US or Holland.

To date, very few studies have specifically examined the needs of Hodgkin lymphoma survivors (Grinyer, 2010), although they have been examined in haematological survivors as a whole (Lobb *et al.*, 2009; Parry *et al.*, 2012; Parry *et al.*, 2011; Swash, Hulbert-Williams and Bramwell, 2014). Younger survivors with haematological cancers displayed the highest levels of unmet needs compared to older adults regarding psychosocial issues, emotional problems such as fear of recurrence, as well as relationship and family issues (Lobb *et al.*, 2009; Parry *et al.*, 2012). Further exploration into the specific support and information needs of Hodgkin lymphoma survivors are therefore warranted. Prospective studies which explore information and support needs over time may be useful. A more in-depth understanding of how patients with Hodgkin lymphoma access different types of support, such as through peers or online interactions, would also be useful to inform intervention development. Studies have shown that haematological survivors may exhibit specific needs around treatment completion (Lobb *et al.*, 2009), so more research into this transition period for Hodgkin lymphoma survivors would inform the provision of support given to survivors by health professionals.

Many studies have demonstrated that demographic, treatment and disease-related variables are often unable to explain the variance in outcomes, so further exploration into psychological variables through qualitative research may yield useful insights. Psychological variables may be important, as many survivors' ratings of global HRQoL were often similar to controls, despite deficits in specific domains, which illustrates that survivors had adjusted to the disease (Roper, 2009). In haematological cancers overall, it was found that coping styles, self-efficacy, assertiveness, spirituality and health beliefs were associated with quality of life, however the authors noted the lack of research in this area (Allart, Soubeyran and Cousson-Gélie, 2013). In Hodgkin lymphoma survivors, psychological variables such as sense of coherence and social support may be important, so more evidence is needed (Soares *et al.*, 2013; Wettergren *et al.*, 2004).

Further studies could also examine survivors' fears of a recurrence and how this is managed. While this was explored in an unpublished qualitative thesis, this relied upon the retrospective accounts of five survivors who were around 20 years post treatment, and the study did not explain the coping strategies used to deal with fears of recurrence (O'Dell, 2010). There is also a need for future research to examine perceptions of late effects, particularly for malignancies such as lung cancer or leukaemia. The impact on relationships amongst Hodgkin lymphoma survivors has also received relatively little attention, particularly how young survivors deal with the impact on family life and romantic relationships, as well as peers. There is very little evidence regarding the impact on body image in Hodgkin lymphoma survivors (Grinyer, 2007; O'Dell, 2010), so further in-depth investigation is warranted. Further exploration into the impact on sexuality and how patients adapt to initial changes may yield more in-depth insights, as all existing studies have focused on sexual dysfunction rather than holistic aspects of sexuality. Due to the lack of research (Horsboel *et al.*, 2012), more research into the transition back into the workplace is warranted to explore how patients could be supported better. Additionally, no studies have specifically examined the psychosocial impact of fertility directly, so more research into patients' experiences of dealing with fertility issues is warranted. In particular, as research shows that beliefs over fertility status may vary (Kiserud *et al.*, 2007), further research could explore this further as well as issues surrounding doctor-patient communication.

3.3.1 Conclusions

To date, the literature on the psychosocial impact of Hodgkin lymphoma lacks coherence, not only due to the deficit of studies, but also due to poor methodological designs. Evidence suggests that Hodgkin lymphoma survivors may be at risk of various late effects, psychological distress, fertility concerns, employment issues, fatigue, poorer HRQoL and sexual impairment, although some of these issues may be transient. This thesis will examine the experiences and needs of younger adults with Hodgkin lymphoma regarding these issues in greater depth.

3.4 Overall summary of literature review chapter

The two literature reviews illustrate that a more comprehensive understanding is needed on the psychosocial impact of cancer on both groups of survivors as these populations are relatively under-researched. In particular, greater knowledge is needed regarding the psychosocial impact of these cancers on several key areas (fertility, work, body image, sexuality, fatigue, psychological wellbeing and relationships) as well as how survivors adjust to these areas. To summarise, further exploration is needed regarding;

- The process of adjusting to the disease, particularly in the period following treatment completion and during early survivorship
- Early survivorship issues; including experiences and supportive care and information needs surrounding the end of treatment transition as well as during early survivorship
- The meaning of quality of life for survivors, and how quality of life and adjustment could be enhanced through interventions
- Younger survivors’ experiences and needs regarding; relationships (peer, family and romantic), body image, fertility concerns, preferences for interventions, work issues, sexuality, illness beliefs, awareness of late effects, psychological wellbeing

- Positive consequences of cancer
- Psychological variables which may influence adjustment, such as coping strategies and perceptions, and the psychological processes involved in adjustment
- Survivors' preferences and use regarding sources of support in relation to unmet needs, and acceptability of different types of support
- The impact on younger survivors, particularly those under 30 years old
- The reasons why some survivors are more vulnerable to the psychosocial effects and the psychological processes which may contribute to adjustment to the different areas affected by cancer

These issues will be explored in this thesis, in order to inform the design of psychosocial interventions for younger adult survivors.

Chapter 4: Methods

4.1 Introduction

This chapter will initially describe the grounded theory methodology employed, followed by the methods of data collection and analysis undertaken. The methodology and methods were chosen to address the study objectives (see chapter 1), which were to develop a detailed understanding of how young adults adjust to the psychosocial impact of cancer, (specifically to Hodgkin lymphoma or testicular cancer), particularly during the transition from treatment to follow-up.

4.1 Methodological approach

4.1.1 Justification for using grounded theory

Grounded theory (Charmaz, 1990; Glaser and Strauss, 1967) was chosen as the most appropriate methodology for this study for a number of key reasons. Firstly, relatively little is known about younger adults' experiences of adjustment to cancer and this methodology is appropriate when there is minimal previous research in the field of interest (Lyons and Coyle, 2007). There are no existing substantive theories of adjustment to cancer in younger adult cancer survivors. Therefore, using a grounded theory methodology will enable a new substantive theory to be developed in this area, which could help explain the phenomenon of adjustment to cancer and inform the delivery of care to young adults. This will also be able to expand upon or even challenge existing theories or frameworks in the area of psycho-oncology, as well as in the wider field (Brennan, 2001; Festinger, 1954; Leventhal, Nerenz and Steele, 1984). This method is, therefore, useful when a topic is not already well-developed theoretically (Lyons and Coyle, 2007). Grounded theory is appropriate when the key research questions involve the exploration of processes, such as those involved in adjustment or coping with cancer (Horgan, Holcombe and Salmon, 2011; Knott *et al.*, 2012). This methodology was also chosen for pragmatic reasons, since simultaneous collection and analysis of data is a key part of grounded theory (Charmaz, 2006) compared to an interpretative phenomenological analysis (IPA) approach for example, whereby data analysis often occurs after data collection has ended (Smith, Flowers and Larkin, 2009). Due to the potentially small numbers of participants eligible for the study and the time restrictions of a doctoral project, conducting data analysis alongside collection was deemed necessary.

4.1.2 Overview of grounded theory methodology

Grounded theory is an inductive and systematic method of qualitative inquiry, which aims to move beyond description and develop a new substantive theory that is 'grounded' in the experiences, words and actions of participants (Charmaz, 2006; Glaser and Strauss, 1967; Strauss and Corbin, 1990). Grounded theory methodology originates in sociological research, and evolved out of research concerning chronic illness (Glaser and Strauss, 1967). The methodology was originally developed by Barney Glaser and Anselm Strauss in the 1960's, in an era of social science dominated by quantitative methods and positivism, where qualitative research was deemed descriptive, unsystematic and biased. Grounded theory was initially put forward as a systematic methodology that would increase the rigour of qualitative research by providing clear guidelines and develop a theory inductively from the data, rather than testing an existing theory or hypothesis (Glaser and Strauss, 1967).

Grounded theory is an evolving methodology, as it continues to be further developed by different theorists, who have debated differences in epistemology, the use of methods, and issues surrounding key concepts (Birks and Mills, 2011; Cutcliffe, 2000; Dunne, 2010). Following an ideological split by its original theorists, several different versions of grounded theory have emerged (Charmaz, 2006; Clarke, 2003; Dey, 1999; Glaser, 1978; Strauss and Corbin, 1990). ‘Classic’ grounded theory advocated by Glaser (1978; 1967) takes the original post-positivist position that themes ‘emerge’ from the data, and that there is a reality which can be ‘discovered’ by the researcher, whereas, Strauss and Corbin’s (2008; 1990; 1998) version of grounded theory is influenced by symbolic interactionism (Blumer, 1969). This framework assumes that individuals actively create meaning through social interactions and communication with others, which is a dynamic process (Blumer, 1969). A social constructivist version of grounded theory was put forward by Charmaz (1990; 2006) and was chosen for this study for several reasons (see below). This approach highlighted the importance of situating the researchers’ epistemological position when conducting a grounded theory study (Charmaz, 2006).

4.1.3 Epistemological position – social constructivism

Epistemology refers to theories of how and what we can know about the world and knowledge (Ritchie *et al.*, 2014). A social constructivist view posits that reality is socially and culturally constructed and that there is no ‘true’ version of reality to be discovered. This view assumes a relativist stance that there are multiple realities to be interpreted and constructed by the researcher. Therefore, this stance assumes that the resulting theory from a study is an interpretation, rather than ‘truth’ (Charmaz, 2006). This social constructivist approach is closest to my own views as the researcher in this study. Charmaz (1990) acknowledges that the researcher brings their interests and personal history, as well as methodological, philosophical and theoretical background to the research process. Constructivist grounded theory takes more of a flexible approach to methodology, which is perceived as a set of guidelines rather than prescriptive rules, as grounded theory was described as a ‘*systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories "grounded" in the data themselves* (p.4) (Charmaz, 2006). This was deemed important, due to the practical constraints of recruiting a younger adult survivor population (see Discussion, chapter 8), which meant that a strict adherence to all of the grounded theory principles, such as theoretical sampling, was not possible. This approach acknowledges both the role of the researcher and the participant in constructing the data and emergent theory (Charmaz, 1990; Charmaz, 2006). This epistemology, therefore, recognises the active rather than neutral role of the researcher in constructing the data (Charmaz, 1990), in comparison to the original grounded theorists view that the researcher is neutral and unbiased (Glaser and Strauss, 1967). Instead, Charmaz (2006) places more emphasis on reflexivity throughout the research process, as constructivists acknowledge their own assumptions and biases and how these might influence the research.

The texts of the original grounded theorists have proved useful for providing information on the key concepts and methods in grounded theory (Corbin and Strauss, 2008; Glaser, 1978; Glaser and Strauss, 1967; Strauss and Corbin, 1990). Later work by Strauss and Corbin (2008; 1998) take a constructivist viewpoint and discuss the importance of reflexivity, however their approach advocates the use of a coding paradigm. This has been criticised as being very complex, and can impose a deductive framework on the data, which might limit analytical insights and risk the researcher ‘forcing’ the data into preconceived categories (Birks and Mills, 2011; Glaser, 1992; Willig, 2008). I wanted to avoid imposing a framework on the data, and so simpler guidelines for coding data by Charmaz were deemed appropriate (Charmaz, 2006). In line with the original theorists, Charmaz (2006) also recommends the use of abductive reasoning, whereby inductive insights are tested out deductively during subsequent data collection, in order to modify the theory, which was the approach used in this study.

4.1.4 Key concepts in grounded theory

Whilst differences are evident between various theorists (Birks and Mills, 2011; Charmaz, 1990; Charmaz, 2006; Glaser and Strauss, 1967; Strauss and Corbin, 1990), grounded theory has several common distinguishing features, which will be described in turn in relation to their use for this study. They include:

- simultaneous data collection and analysis
- theoretical sampling
- analytical and theoretical coding and categorisation
- generation of a theory
- constant comparison method
- memo writing
- theoretical sensitivity
- delaying of the literature review
- theoretical saturation

A grounded theory study usually begins with the generation of several general research questions, which will often evolve as the analysis progresses, which was the case in this study (Charmaz, 2006). The *simultaneous collection of data alongside analysis* employed in this study, meant that any analytical or theoretical hypotheses or ‘hunches’ formed throughout the research process were able to be followed-up and tested out (Charmaz, 2006). *Theoretical sampling* is another key feature of grounded theory, which is a type of purposive sampling. This approach involves directing further sampling according to the researchers tentative hypotheses surrounding emergent theoretical categories, which could involve sampling a different participant group or negative cases, for example (Glaser and Strauss, 1967). Theoretical sampling can add further validity and rigour to the developing theory, and allows for the exploration of gaps in the emerging categories. In this study, theoretical sampling was not possible as the small number of eligible patients meant it was more important to recruit all who were willing to take part. However, a theoretical sampling approach was initially attempted, as health professionals were asked to invite patients with non-Hodgkin lymphoma into the study, so that these patients could be a source of comparison, as they have a poorer prognosis. None were recruited however, as only small numbers fitted the inclusion criteria and these patients did not respond to the invitation letter. It was not possible to theoretically sample negatively adjusted cases, as these patients would only be identified during, and not before, the interview. Another key feature of grounded theory is *theoretical saturation* (Glaser and Strauss, 1967) which involves the testing out of theoretical categories in further data collection until no new categories are emerging. While theoretical sampling was not employed, theoretical saturation was achieved in this study, as no new categories were emerging from subsequent interviews. Categories identified in the analysis were sufficiently well developed to enable the development of the theory (see Chapter 5).

The constant comparative method is another key element of grounded theory that was employed, whereby data is constantly compared with data, such as 'code with code' or 'incident with incident' (Charmaz, 2006). A grounded theory study should *generate a new theory* inductively from the data following a process of *analytical and theoretical coding* of the data. A theory has been defined as an '*explanatory scheme comprising a set of concepts related to each other through logical patterns of connectivity'* (p.113) (Birks and Mills, 2011). A grounded theory is typically a middle-range or substantive theory that *explains* the phenomenon under study (Charmaz, 2006). Rather than confronting or trying to synthesize with existing theories, a grounded theory should aim to transcend existing theories (Glaser, 1978). *Memo writing* is a vital component of the methodology which was employed, whereby the researcher's informal analytic ideas are constantly noted throughout the research process, as a form of reflexive practice (Charmaz, 2006; Corbin and Strauss, 2008; Glaser, 1978; Strauss and Corbin, 1990). Memo writing has been described as "*a pivotal intermediate step between data collection and writing drafts of papers"* (p.72) (Charmaz, 2006). *Theoretical sensitivity* is another key concept in grounded theory relating to the personal qualities of the researcher such as insight and creativity (Charmaz, 2006; Glaser, 1978; Strauss and Corbin, 1990). In this study, theoretical sensitivity was developed by reading the wider literature as well as drawing upon professional and personal experience (Strauss and Corbin, 1990).

One of the key debates in grounded theory is the timing and use of the literature review, which was an issue in this study (Cutcliffe, 2000; Dunne, 2010; Giles, King and de Lacey, 2013). In contrast to many existing methodologies, Glaser (1978; 1967) argued for a complete delay in reviewing the literature in order to avoid 'forcing' the data into preconceived categories which might contaminate the inductive process. Charmaz (2006) also discussed how delaying the literature review encourages originality, but did acknowledge practical considerations. Elsewhere, this approach has also been criticised on pragmatic grounds, as many researchers need to conduct a literature review prior to starting a project in order to complete grant applications (Dunne, 2010). For this study, an initial scoping review of the literature was undertaken. This was necessary in order to assess under-researched areas requiring further study, inform the design of the study, as well as to put forward a research protocol for review by ethics committees. This also ensured that I was not naïve to the current state of the literature and helped development of the interview schedule. This approach is supported by other researchers who have argued that no researcher is an 'empty vessel' and that each researcher has a disciplinary, theoretical and personal background which they bring to the study (Cutcliffe, 2000). It has also been stated that an early literature review might provide a solid rationale for the study, ensuring that the study does not '*reinvent the wheel*' (Dunne, 2010). From commencement to the mid-phase of data collection and analysis I minimised reading empirical and theoretical literature. A complete and systematic search of the literature (see Chapters 2 and 3) was delayed until over approximately two-thirds of the interviews had been completed and the analysis was well-developed. During the latter stages of data analysis, the literature was used as a source of comparison and at enhancing theoretical sensitivity. Researchers have argued that the use of reflexivity and memo writing can be helpful at promoting awareness of how the researcher might have been influenced by the literature, which was used in this study (Dunne, 2010; Giles, King and de Lacey, 2013). Charmaz (2006) also advocates the need for researchers to engage with existing literature and to demonstrate how the grounded theory fits or extends previous work, which was also employed during the analysis and draft writing stages of this project.

4.2 Study design

A qualitative, longitudinal design was employed involving face-to-face semi-structured patient interviews over two time points. A grounded theory methodology was also employed based on a social constructivist epistemology.

4.2.1 Rationale for selecting a qualitative approach

A qualitative methodology was employed for several reasons. Firstly, there is a lack of existing research in this area and qualitative methods are useful at increasing knowledge in poorly understood and complex areas (Pope and Mays, 1995; Ritchie, 2003). Qualitative research aims to describe, explain and interpret phenomena, which was deemed necessary to address the study objectives (Ritchie, 2003; Willig, 2008). Qualitative methods also enable the researcher to elicit rich and detailed data, and gain an in-depth perspective into how individuals' subjectively experience phenomena, such as illness and healthcare (Mays and Pope, 2000; Ritchie and Lewis, 2003). Qualitative methods may also be more appropriate for potentially emotional and sensitive topics, such as cancer, as they 'give voice' to vulnerable individuals (Ritchie, 2003). Although taking part in qualitative research often involves a greater time burden on participants compared to quantitative approaches, such as questionnaire surveys, there may be several positive consequences. Qualitative methods often allow for greater contact between the participant and researcher, who can be on hand if participants should become distressed or require signposting to support services. Due to the greater time investment in sharing their illness and healthcare experiences, participants may also feel they have made a greater contribution to knowledge and have helped others in a similar situation (Lowes and Paul, 2006). As demonstrated by the literature reviews undertaken (Chapter's 1, 2 and 3), the majority of previous research has been quantitative and there is a relative lack of studies using qualitative methods on the topic of interest. A qualitative approach was therefore used to enable exploration of the complexities of psychosocial adjustment to cancer in younger adults and gain a new insight into this understudied phenomenon.

4.2.2 Semi-structured interviews

Semi-structured interviews, selected as the data collection method in this study, are the most widely used qualitative method (Willig, 2008). It has been stated that semi-structured interviews should resemble a '*conversation with a purpose'* (Burgess, 1982), as they are to an extent, directed by the researcher who has a pre-set agenda (Kvale and Brinkmann, 2009). However, this method allows for flexibility and enables the participant to respond to broad questions in their own words, and the researcher is able to follow-up on any unanticipated issues that may arise. Questions are open-ended, so participants are free to say as much or as little as they want to, and are given the opportunity to discuss anything of importance to them in relation to the topic area. This approach enables more detailed answers to be elicited compared to a structured interview method or questionnaire design, where participants' answers are constrained by the confines of the questions. Another advantage of using the interview method is that participants may also feel more able to discuss personal issues than they would in a group setting, such as a focus group where group dynamics may be affected if participants are strangers (DiCicco-Bloom and Crabtree, 2006; McLafferty, 2004).

Face-to-face interviews were chosen as this method enables the researcher to build rapport with the participant and be on-hand to offer support should participants become distressed, which was deemed appropriate for this topic (Braun and Clarke, 2013; DiCicco-Bloom and Crabtree, 2006; Willig, 2008). The rapport between researcher and participant may be harder to develop during telephone interviews, due to the lack of visual non-verbal communication, and this could negatively affect the quality of the interview data. Some evidence suggests that participants may also derive potential therapeutic benefits from taking part in research interviews (Adams, 2010; Birch and Miller, 2000; Colbourne and Sque, 2005; Morecroft, Cantrill and Tully, 2004). Previous interviews with male cancer patients, including men with testicular cancer, found that men valued telling their story and talking about their worries with someone who wasn't a family member or responsible for their healthcare (Colbourne and Sque, 2005). The research interview was deemed important by men in helping them come to terms with cancer, with interviews appearing to be a form of serendipitous therapy (Colbourne and Sque, 2005). The current study collected data during the post-treatment phase which is a period when patients can be absent from work on medical grounds and may feel abandoned by their healthcare team (Parry *et al.*, 2011); and hence may value the interest from the researcher during this period.

It is important to recognise that issues such as power dynamics between the researcher and participant may arise during interviews (Braun and Clarke, 2013; Oliffe and Mróz, 2005). Social class, age, or gender differences between participant and researcher may affect power dynamics, which may influence the data gathered. These can be acknowledged and addressed by the use of reflexivity, which was employed in this study and described later on in this chapter and in the Discussion (Chapter 8). Power dynamics may impact on the quality of the interviews by affecting the willingness of the participant to discuss their concerns and reveal their feelings and views to the researcher. Other disadvantages of the interview method are mainly related to ethical considerations, as participants may reveal emotional concerns for the first time, which has the potential to cause distress or harm to the participant, which was an initial concern for this study (DiCicco-Bloom and Crabtree, 2006). Issues with a female researcher (myself) interviewing male participants may also arise, including issues of safety (Lee, 1997).

4.2.3 Longitudinal design

A longitudinal qualitative approach was chosen to enable exploration of participants' experiences of illness over the passing of time (Calman, Brunton and Molassiotis, 2013; Murray *et al.*, 2009). This was deemed appropriate when exploring the topic of adjustment to cancer, described previously by Brennan (2001) as an ongoing and dynamic process involving transitions. Researchers have called for more longitudinal studies to explore the process of transitions over time (Kralik, Visentin and Van Loon, 2006). Previous research has also demonstrated the value of longitudinal qualitative designs in health and psychology research and in the cancer survivorship field (Drevdahl and Dorcy, 2012; Grunfeld and Cooper, 2012; Kennedy, Harcourt and Rumsey, 2012; McCaughan *et al.*, 2012; Pinnock *et al.*, 2011; Taylor, Richardson and Cowley, 2011). Longitudinal interviews allow the researcher to analyse the social processes involved in a phenomenon in greater depth, and identify how participants experience, adapt and respond to change and develop over time (Hermanowicz, 2013). According to Holland *et al*, (2006) this method can *"offer fresh perspectives into established arenas of social enquiry, drawing attention to the psychological and biographical processes ('lived through experience') through which social outcomes are generated and mediated"* (p.2). This approach might also lead to the development of greater rapport between the participant and researcher, so the participant might openly disclose more personal and rich data (Hermanowicz, 2013). Altogether, this might improve the quality of the interviews, and might be useful for participants who are less forthcoming initially with their responses. This approach might also further improve the potential for therapeutic benefit of the interview (Calman, Brunton and Molassiotis, 2013; Colbourne and Sque, 2005). Another strength of qualitative longitudinal research is that the questions posed to participants at different time points might differ, and participants can be asked selectively similar questions as well as questions stemming from emerging themes from the analysis (Hermanowicz, 2013). This was deemed beneficial when exploring the experience of younger adults during the transition to survivorship, as different issues across this recovery period were anticipated based on existing research (Hauken, Larsen and Holsen, 2013; Vaartio, Kiviniemi and Suominen, 2003; Zebrack *et al.*, 2014d) and so could be followed up.

A longitudinal approach might, however, increase the risk of greater participant attrition, pose a greater time and emotional burden on the participant, and might also affect the researcher if they witness participants becoming ill (Calman, Brunton and Molassiotis, 2013; Hermanowicz, 2013). The circumstances of the participant might also have changed over time, so the researcher needs to consider the changing context for each participant, which might add greater complexity to the analysis. In this study, the occurrence of a cancer relapse was not anticipated at the outset, due to the good prognoses for both testicular cancer and Hodgkin lymphoma survivors (Cancer Research UK, 2014p; Cancer Research UK, 2014w). The building up of this relationship might pose challenges regarding the role of the researcher in terms of setting boundaries, as previous studies show that participants might inappropriately contact the researcher for advice in between interviews (Calman, Brunton and Molassiotis, 2013). To date, there is a lack of agreement over the design of this approach and no consensus exists regarding the definition of what constitutes longitudinal qualitative research (Calman, Brunton and Molassiotis, 2013; Holland, Thomson and Henderson, 2006). Some researchers have argued that interviews should be over at least two time points, which was the approach taken in this study, although others state interviews should be at least a year apart, which was not possible for this project due to time restraints of a doctoral project (Calman, Brunton and Molassiotis, 2013; Holland, Thomson and Henderson, 2006).

4.3 Participant selection, recruitment and data collection

4.3.1 Defining a 'younger' adult cancer survivor

There has been considerable debate amongst experts regarding how to define a 'younger' adult cancer survivor, particularly where the upper age limit should lie (Aubin, 2011). The differences in health care and funding systems between different countries no doubt contributes to the division amongst experts regarding this issue (Aubin, 2011). In the UK, a children and young adult cancer survivor work stream has evolved from the NCSI, which extends up to age 24 years (NHS Improvement, 2010). This age range of 15-24 years is commonly referred to as the teenage and young adult group in the UK, differentiating from 'middle adults' or those between 25-49 years old (Cancer Research UK, 2013a). In the US, the NCI defines the younger adult cancer survivor group as extending up to 39 years (Adolescent and Young Adult Oncology Progress Review Group, National Cancer Institute and LIVESTRONG Young Adult Alliance, 2006). It has been argued that there should be a flexible approach to specifying the age range, due to the amount of individual variation in achieving key developmental milestones (Aubin, 2011). Some experts argue that the 15-24 age group have specific concerns, such as dating, university, establishing identity and independence, while for 25-39 year olds, issues such as fertility, young children, maintaining relationships, careers as well as financial independence might be more salient (Aubin, 2011).

For this thesis, the age range of 20-45 year olds was selected as the inclusion criteria. This took into account the increasing age in which issues such as fertility and marriage are a concern for adults in the UK. Data shows that approximately 20% of births in the UK are in women between 35-45 years old (Office for National Statistics, 2013b). There has also been an increase in the mean age at marriage in the UK, which currently lies at 36.3 years for men, and 33.8 years for women (Office for National Statistics, 2013a). Socio-cultural issues, such as the rise in student debt and the cost of buying a house in the UK, mean that the age at which younger adults are able to achieve independence from parents is also increasing (Kelly and Gibson, 2008). Cancer types that are common in younger adults, as opposed to older adults or children, such as testicular cancer or Hodgkin lymphoma are often found in those in their 20's and 30's (Cancer Research UK, 2015h). A UK charity, Shine Cancer Support, is specifically aimed at supporting those living with cancer in their 20's, 30's or 40's, which suggests that the UK teenage and young adult age range of 15 -24, which informs policy, does not reflect the age-specific needs of those aged 25-40. This UK age range is also determined by a medical model, as it is based on Cancer Research UK statistics data.

4.3.2 Patients

The target population for the study was younger adult cancer survivors treated with curative intent between 20-45 years old. However, as only small numbers of patients were expected to be eligible from one tumour group at the study sites, patients with two types of cancer were recruited. The sample included patients with Hodgkin lymphoma or testicular cancer, as both cancer types are prevalent in young adulthood and have a good prognosis (see Chapter 1 for further explanation) (Cancer Research UK, 2014p; Cancer Research UK, 2014w). The selected age range was chosen to include the NCI's (2013) definition of young adulthood as extending up to age 39. Due to expectations of small numbers of patients recorded by the Cancer Network, the criteria were extended up to age 45.

4.3.3 Sample

Convenience sampling was employed to recruit participants, whereby all patients who met the inclusion criteria were invited into the study (Patton, 1990). The eligibility criteria used in the study were as follows:

Initial inclusion criteria

1. Diagnosed with Hodgkin lymphoma or testicular cancer
2. Aged between 20-45 years old
3. Recently (< six months) completed primary cancer treatment
4. Treated with curative intent

Amended inclusion criteria

Originally, only patients completing initial treatment were included in the sample, however some of the participants had a relapse, which was not anticipated, so an ethical amendment was obtained to amend the inclusion criteria (point 3) to also include:

- Recently (< six months) completed primary or second line treatment or treatment for a recurrence of cancer

Exclusion criteria

1. Unable to participate in a face-to-face interview or speak fluent English
2. Patients who had a major medical comorbidity, as identified by the patient's consultant oncologist
3. Patients requiring palliative care including complex or advanced symptom control or end-of life care

4.3.4 Ethical approval

Ethical approval was obtained from Oxford Brookes University in February 2012 and then from the South Central Oxford C National Health Service (NHS) research ethics committee in May 2012 (REC reference 12/SC/0215). Research governance approvals were obtained from three hospital sites in a former Cancer Network area, which were all approved by September 2012. Recruitment began at two regional cancer centres and a local cancer unit in a district general hospital. Due to slower than anticipated recruitment rates, ethical approval was sought from an additional cancer centre in another former Cancer Network region, which was obtained in February 2013.

4.3.5 Recruitment

The sampling approach involved screening consecutive patients for study eligibility, and inviting all eligible patients into the study. Eligible patients were identified by the clinical oncology team either during multi-disciplinary team meetings (MDT), or during oncology clinics by the Clinical Nurse Specialist (CNS). The study was initially mentioned to patients by the clinical team (CNS or Oncologist) during an oncology appointment for treatment at the hospital, so that potential participants were aware of the study. Patients were then given information about the study by their clinician or CNS during a clinical appointment at the end of their treatment or at their first follow-up appointment. Health professionals offered patients an information pack to take away containing an invitation letter, an information sheet, response form, and a stamped addressed envelope (see Appendix 1-3). Potential participants were asked to return a response form to the researcher within two weeks if they were interested in participating. Alternatively they could respond via text, email or telephone if this was more convenient. The majority of participants responded using the response form. If the participant had not responded six months after receiving the information pack, they were deemed a non-responder. Hospitals were chosen as the sole recruitment source, so patients could be recruited as they finished initial treatment.

The final sample included 28 participants (10 Hodgkin lymphoma and 18 testicular cancer patients). The convenience sampling method employed was successful in including participants with a range of views and experiences and with different work and educational backgrounds. The original aim was that 30 patients would be recruited into the study, in order to elicit a range of views. Although 30 patients responded to the initial invitation, only 28 were recruited, as two patients failed to respond further following initial telephone contact. Recruitment of participants with testicular cancer ended in March 2014, and in July 2014 for Hodgkin lymphoma patients. All Time 2 interviews were completed by February 2014 for the testicular cancer sample, and by September 2014 for Hodgkin lymphoma patients. Overall, the total recruitment period for the study was two years (September 2012-September 2014).

4.3.6 Data collection

4.3.6.i Interviews

Face-to-face interviews with patients were conducted within six months of treatment completion (Time 1) and approximately six months later (Time 2). I telephoned participants who responded to the initial study invitation to explain the study in greater detail, answer any questions and arrange a convenient time and location for the interview. The location of the interviews is presented in Table 1, which varied according to the preference of the participant. The interviews were conducted in several counties in the south west and south central regions of England. Participants were sent a text message on the evening before or morning of their interview to check they were still available and happy to participate. This acted as a reminder and in some cases this led to rescheduling of the interview date if it was no longer convenient.

Table 1: Locations of interviews

Interview Location	**Time 1, n=28** N (%)	**Time 2, n=20** N (%)
Home	20 (71)	19 (95)
Work	3 (11)	1 (45)
Public Cafe	5 (18)	0 (0)

Before each interview commenced, I attempted to establish good rapport with the participant, in terms of pre-interview ‘chit-chat’ (Braun and Clarke, 2013; DiCicco-Bloom and Crabtree, 2006). This is an essential part of the research process, and aimed to build trust and mutual respect, and help the participant feel comfortable with talking about their experience (DiCicco-Bloom and Crabtree, 2006). Before each interview at Time 1 and Time 2, written informed consent was obtained (see Appendix 4). On the consent form, participants were reminded of the statements regarding confidentiality and anonymity, and were reassured that they did not have to answer anything they were not comfortable with, and could withdraw from the study at any time, without giving a reason. They were also asked to complete a brief demographic questionnaire prior to the start of the interview (see Appendix 5). With patients’ consent, interviews were digitally recorded. A semi-structured interview schedule was used during interviews with participants (see Appendix 6-7). The interview schedule developed for the study had input from a cancer survivor representative (n=1), from a former Cancer Network Consumer Research Partnership group, and a Hodgkin lymphoma cancer survivor known to the research team (n=1). The interview schedule was also informed by a preliminary scoping of existing literature on this topic and from discussions with expert health professionals in this field. Interviews began with an open-ended question of *‘tell me about your experience of having cancer from when you first heard about your diagnosis?’* to encourage participants to talk about their diagnostic and treatment experiences. Subsequent questions focused on their experiences once treatment had finished. A summary of the key topic areas from the interview schedule is presented below;

- Experience of the transition from treatment to follow-up
    - Feelings/emotions about ending treatment
    - Experience of discharge appointment/any follow-up appointments
    - Feelings/emotions since ending treatment
    - Experience of talking with doctor/nurse
- The psychosocial impact of having cancer
    - Impact on physical wellbeing
    - Impact on home life
    - Impact on social life and relationships
    - Impact on feelings and self-confidence
    - Impact on work
    - Future plans
    - Impact on body image and plans for parenthood
    - Positive aspects of experience
- Challenges and how they are managed
    - Most problematic challenges since finishing treatment
    - Strategies (psychological, practical) to manage challenges
    - Sources of helpful or unhelpful support
- Needs (met and unmet) since the end of treatment
    - Information needs
    - Supportive care needs
- Improvements to care service

    - Ideas for improvements in care provision for younger adults

All questions were open-ended, and 'prompts' were used during interviews to elicit more detailed responses to questions, and to seek clarification about specific areas (for example, '*how did that make you feel*?'). Participants were free to discuss any issues of concern to them, and unanticipated topics which arose outside of the interview guide were followed up. As data analysis and collection progressed, more questions were added to the interview schedule based on the emerging themes, so the interview schedule became more focused, as some questions were discarded. An example of a question that was added included '*How significant do you think having cancer has been for you?'*. After each interview, participants were asked if there was anything else they would like to discuss which had not been included in the interview schedule. They were also asked how they found the interview and were thanked for their time. I often stayed to talk to the participant after the tape was turned off to ensure they were happy, and willing to be contacted about the Time 2 interview. Participants were made aware that if they wished to withdraw from the study at any time, they could contact me through email, text or telephone. Following each interview, field notes were written. This aimed to record initial reflections on the interview, including overall impressions, non-verbal behaviour, initial ideas for themes or codes, or anything that was discussed before or after the interview.

Approximately six months after Time 1 interviews, participants were telephoned or sent an email to check that they were still happy to participate and a suitable time and date for the second interview was arranged.

Although the aim was for Time 2 interviews to take place approximately six months after Time 1, delays were common due to participants' work and family schedules. Before attending each Time 2 interview, Time 1 transcripts were re-read. This acted as a reminder of what each participant said, and specific issues at Time 1 were noted down in order to ask participants about these at Time 2. For example, one participant at Time 1 expressed concerns over having a delayed emotional impact to cancer, which he was told would be likely by his clinician. Therefore, at Time 2, I asked the participant about whether this had occurred in the time since the first interview. At Time 2, interviews began with asking participants '*tell me how has the last 6 months has been for you?*'. The interview schedule at Time 2 was selectively based on the schedule at Time 1, and a few new questions were added to explore the emerging theoretical concepts (e.g. *'To what extent do you worry about your health in the future?'*). Participants were asked about their views regarding emerging ideas surrounding implications for interventions; such as peer support for instance (e.g. '*What do you think about a system whereby people who have been through treatment could support others with cancer*?'). In asking similar questions at Time 2, the participant was encouraged to discuss if any perceptions, experiences and needs had changed over time. This was in line with guidance from Hermanowicz (2013), which outlined one approach to longitudinal data analysis whereby only a selected number of identical questions are posed to participants, and more questions are added based on the developing analysis. However, in many cases, particularly for the testicular cancer sample, participants felt there had been few changes by

Time 2, so in this instance, the second interview acted to gain a deeper and richer insight into their experiences.

The lone worker policy procedure outlined by Oxford Brookes University was employed when conducting interviews. This involved making sure a contact was in place for the time of the interview, usually one of the supervisory team or a senior staff member, who was aware of the participant's name, address, and time and date of the interview. A text message was sent to the contact before starting the interview, and again once I had left the location of the interview. For patients with Hodgkin lymphoma, interviews at Time 1 lasted between 40 and 90 minutes (mean=60 minutes) and Time 2 interviews lasted between 40 minutes and 110 (mean=65 minutes). For patients with testicular cancer, interviews lasted between 40-120 minutes at Time 1 (mean=70 minutes) and between 30-70 minutes at Time 2 (mean=50 minutes).

4.4 Data Analysis

4.4.1 Data entry and storage

After each interview (typically several days or weeks later), I transcribed verbatim the majority of the interviews (n=37) and any identifiable information, such as names or places, were anonymised. Participants were also assigned a unique number to ensure confidentiality (e.g. P1). Due to time restraints, another transcriber who was bound by a confidentiality agreement transcribed some of the interviews (n=11) towards the end of the data collection phase. For all transcripts, a further quality check of the data was conducted, as I went over the audio recording and the transcript to ensure accuracy. This also contributed to the analysis, as on-going analytical notes were made during this process. In order to ensure confidentiality, participant data were stored on a password protected computer. Hard copies of transcripts, questionnaires, and consent and response forms were stored in a locked cabinet in a secure room at Oxford Brookes University.

4.4.2 Initial coding

When analysing the qualitative data, guidelines outlined by Charmaz (2006) were employed. Firstly, initial line-by-line codes in the left hand side margin were systematically assigned to the transcript. Coding was guided by Charmaz's (2006) definition; *"take segments of data apart, name them in concise terms, and propose an analytic handle to develop abstract ideas for interpreting each segment of data.*" (p. 45). The initial codes aimed to describe each particular section of data, and words were used which emphasised participants' actions and processes involved in their experiences. 'Gerunds' or action words (*avoiding, striving, escalating,* for instance) were used for the majority of codes, where appropriate (Charmaz, 2006). In addition, known concepts from the psychological and sociological literature were also occasionally used as codes, such as sense of coherence (Antonovsky, 1987), self-efficacy (Bandura, 1982) or illness perceptions (Leventhal *et al.*, 1997) for example, in order to improve the conceptual and analytical insights into the phenomenon. The processes in the data were explored, as well as participants' feelings and thoughts during the process and how these developed (Charmaz, 2006). Hidden assumptions, actions and meanings in participants' accounts were examined during coding (Charmaz, 2006). Charmaz (1990) outlined key questions to continually elicit from the data which were employed, including; *"how?", "why?" "Under which conditions?";"With which consequences?" How do people construct beliefs? How do they manage their lives? Why do they think, feel, and act the way that they do? Under which conditions do they think, feel, and act that way? What are the consequences of their beliefs, feelings, and actions?* (p. 1165). During the analysis, I identified whether there were any gaps in the data that could be explored further during the follow-up interview with the same participant as well as with new participants.

4.4.3 Focused coding

The next stage involved *focused coding,* whereby I systematically coded the transcript with more conceptual and analytical codes, on the right side margin of the transcript (Charmaz, 2006). This stage of the coding process was more selective in terms of coding the useful and significant codes arising from the analysis and those which were pertinent to the research question. This required *theoretical sensitivity,* which developed throughout the process. The process of focused coding moved the analysis to a higher conceptual level and enabled larger segments of data to be sorted and organised into categories and sub-categories (Charmaz, 2006). Throughout the analysis, the constant comparative method was used to compare statement with statement, incident with incident, and category with category, both between and within participants. Categories and codes were constantly revisited, which was a continual cycle during the research process. Attention was given to language and emotions used by participants. Negative or deviant cases were also explored, which yielded useful comparisons with the data, illuminating participants' adjustment trajectories (see Chapter 6). The emerging categories were compared to existing concepts and theories in the literature, which were used as a source of comparison, which helped enhance theoretical sensitivity (Birks and Mills, 2011; Glaser, 1978). This was also influenced by my academic background in health psychology, which meant that I was already aware of several of these existing concepts, but attempted to keep an 'open mind' throughout the process of analysis (Charmaz, 2006). A worked example of how initial codes and focused codes were applied to a transcript is provided in Appendix 8.

4.4.4 Theoretical coding and theory development

For each transcript, a Word document was compiled that was usually a 5-6 page summary of the initial and focused codes, in order to organise them into categories. This was then followed by a process of theoretical coding, whereby overarching categories were examined in the data for individual participants. Theoretical coding aimed to build the analytical story between the different codes and categories. Constant comparison was then used to examine categories between different participants as a whole, such as the similarities and differences between participants with testicular cancer and Hodgkin lymphoma. The whole process was iterative, as categories were constantly revisited as the analysis developed. This involved the process of induction, followed by deduction, whereby theoretical ideas and hypotheses were further tested out through subsequent data collection (Charmaz, 2006). A preliminary theory was developed after 10 interviews were conducted. This theory was then tested out, refined and expanded during subsequent interviews. Relationships between concepts were explored, in terms of how they appeared to affect each other and influence participants' thoughts, feelings and behaviours. Due to differences between the two participant groups (testicular cancer vs. Hodgkin lymphoma) in terms of experiences, treatment duration and intensity, the data were analysed both separately and together as a whole (see Chapters 6 and 7). A theory of adjustment to cancer was developed over the course of the data collection and analysis phase, which combined the data from both groups of survivors. As advocated by Charmaz (2006), during the development of the initial theory, diagramming was employed in order to help conceptualise links between categories. During this process of theoretical coding, a core category was developed which provided explanatory power for the analysis (Glaser, 1978), and formed the basis of the theory. An illustration of how theoretical codes were derived from the data, and how these developed from focused coding is provided in Appendix 9.

4.4.4.i Worked examples

Two worked examples are presented below to illustrate how initial, focused and theoretical codes developed and contributed to the theory. The first example is taken from the participant who was the negative case example (see chapter 6), a testicular cancer survivor. This example illustrates how codes were developed about the process of *holding onto negative illness perceptions and a generalised view of cancer.* The second example is taken from a participant who was a particularly positively adjusted case. This example illustrates how codes were developed surrounding the process of *holding onto positive illness perceptions of cancer as a specific disease and a transient threat.*

Table 2: Worked example of code development: negative adjustment

Progression of coding	Codes
Initial codes	Hearing about other people dying of cancer Associating cancer with death Seeing testicular cancer as connected to other cancers
Focused codes	Perceiving testicular cancer as part of one whole disease Increased feelings of susceptibility to a recurrence in another part of the body Rejecting discourse around testicular cancer being the most treatable cancer Finding positive discourse surrounding cancer undermining
Theoretical codes	Taking a generalised view of cancer Perceiving cancer as a chronic threat (not an acute threat) Holding negative illness perceptions
Process in the theory	Holding onto negative illness perceptions and a generalised view of cancer

Table 3 Worked example of code development: positive adjustment

Progression of coding	Codes
Initial codes	Seeing testicular cancer as ‘the best cancer to get’ Feeling grateful for the shorter treatment duration of testicular cancer compared to other cancers Feeling grateful for the high cure rate of testicular cancer
Focused codes	Compartmentalising the threat of testicular cancer Distinguishing between testicular cancer and other cancers Holding onto the view that testicular cancer is the most treatable cancer Finding positive discourse surrounding testicular cancer reassuring
Theoretical codes	Taking a specific view of testicular cancer Perceiving testicular cancer as an acute threat (not a chronic threat) Holding positive illness perceptions
Process in the theory	Holding onto positive illness perceptions of cancer as a specific disease and a transient threat

4.4.5 Longitudinal data analysis

There is a general lack of guidance regarding the procedures used for coding and analysing longitudinal qualitative data, and it has been acknowledged that further research is needed to develop this area (Calman, Brunton and Molassiotis, 2013; Hermanowicz, 2013; Holland, Thomson and Henderson, 2006). Longitudinal interviews can be analysed both cross-sectionally and longitudinally, which was the case in this study (Holland, Thomson and Henderson, 2006). Interviews at Time 1 were analysed typically around a week or two after the interviews took place (before Time 2 interviews). The interviews at Time 2 were initially analysed using the same processes described above, as a cross sectional interview. At Time 2, as the analysis had developed, focused coding for Time 2 interviews became more specific. Attention was given to the contextual conditions of the participants and whether this seemed to influence the interview (Hermanowicz, 2013). For example, if they had developed a new relationship, had a recurrence or changed careers. Once focused codes were grouped into categories, both Time 1 and Time 2 interviews were examined together to explore similarities and differences over time. As the analysis emerged, it was evident that for many participants, there was little change over time, with only a minority experiencing significantly different views and experiences over time, with most participants improving gradually. This has been shown in previous research whereby longitudinal interviews were used to confirm the properties of theoretical categories and so were not presented as a longitudinal narrative (Taylor, Richardson and Cowley, 2011). For each participant, a table of categories from Time 1 and Time 2 interviews was constructed which included any longitudinal themes. Again, the process of constant comparison was employed to compare within and between participants (see Appendices 10 and 11).

4.4.6 Organising the data

Microsoft Word tables were used to assist with organising categories. These tables were used to retrieve relevant quotes from participants, assisted with writing, and enabled further comparisons between participants. The use of a qualitative software program was considered and initially used for some of the initial interviews; however it was felt to be overly time consuming and laborious for a study of this size.

4.4.7 Reflexivity and memo writing

Reflexivity is deemed a vital part of qualitative research, and involves an awareness of the researcher's role in shaping the research process (Willig, 2008). This includes epistemological reflexivity, whereby the researcher reflects upon their assumptions made throughout the research process regarding the nature of reality, knowledge and the world (Mays and Pope, 2000; Willig, 2008). Personal reflexivity is also important, where the researcher reflects upon personal characteristics and biases they may have, such as experiences, theoretical assumptions, research training, personal experiences of the research topic, pre-existing views as well as core values and beliefs, which might have influenced the research (Mays and Pope, 2000; Willig, 2008). In this study, a detailed reflexive research diary was used throughout the entire research process to record any thoughts or reflections of each interview as well as thoughts regarding emerging codes or analytical ideas (Mays and Pope, 2000). Memo writing was also used as part of the analysis (Charmaz, 2006; Glaser, 1978) as memos were written to explore and develop the emerging categories. The purpose of writing memos also helped explain tentative theoretical categories and the relationships between them, and identify where gaps in the theory lie (Charmaz, 2006; Strauss and Corbin, 1990). After each interview, memos were written for each category and sub-category, and then reflections on the memos were also recorded, in terms of questions for further interviews or analytical ideas. Memos were initially descriptive and became more analytical over the course of the data analysis. They were vital in assisting with development and refinement of the analysis and theory. Writing the draft was also seen as an important stage in the data analysis process, and helped to further refine the theory (Charmaz, 1990).

4.5 Issues surrounding 'quality'

4.5.1 Maximising trustworthiness

Qualitative research has been criticised for lacking reproducibility, generalisability and scientific rigour (Mays and Pope, 1995) and there has been extensive debate over what constitutes a 'quality' qualitative research study (Seale, 1999a). The emphasis on ensuring reliability and validity led qualitative researchers to come up with a wealth of different ways of defining quality (Morse *et al.*, 2008; Seale, 1999a). Lincoln and Guba (1985; 2007) established criteria for a 'quality' study, which included; credibility, transferability, dependability, confirmability and authenticity, achieved through practices such as leaving an audit trail, member checking, negative case analysis, peer auditing and reflexivity (Lincoln and Guba, 1985). Seale (1999a) argued that although quality is important, criterions often conflict with the constructivist stance over the inability to establish a universal ‘truth’, due to assumptions over multiple realities. He stated that *“‘quality’ is a somewhat elusive phenomenon that cannot be pre-specified by methodological rules”,* however he felt that quality guidelines could help the researcher in “*moving toward good quality work”* if used appropriately (p. 471) (Seale, 1999a). In this study, several procedures were undertaken to enhance trustworthiness and deepen understanding of the phenomenon. During the initial interviews, the study supervisors (EW and MB) listened and commented on some of the interviews (n=4, Time 1, n=2, Time 2) and we met to discuss the developing analysis. The supervisory team commented on themes and suggested anything that could be explored further in the analysis or in subsequent interviews. Another member of the cancer care research group at Oxford Brookes University independently analysed a section of one transcript of a participant with testicular cancer at Time 1. For Time 2 interviews, two supervisors both independently analysed different sections of a transcript of a Hodgkin lymphoma participant. Emerging themes and concepts from the data were discussed and there were no major discrepancies between researchers. The ongoing analysis was discussed at supervisory meetings, and the developing theory and model was discussed with the cancer care research group. Preliminary findings of the analysis on the testicular cancer sample were also presented at several conferences. The theory was also discussed with a testicular cancer CNS involved in recruitment, who felt the themes were relevant and useful.

While the technique of triangulation was only minimally employed, in terms of gaining multiple researcher perspectives on the data, it has also been critiqued (Seale, 1999a). Researchers have placed it in a more constructivist paradigm, arguing that carrying out these procedures does not guarantee validity, but might deepen understanding (Silverman, 2013), which was the case in this study. Another procedure; member checking (Lincoln and Guba, 1985), whereby participants are asked to verify either a transcript or the final themes (Seale, 1999f) was not employed in this study for several reasons. Firstly, it has been argued that this technique could paradoxically threaten validity, as the data might have been taken to an abstract level, yet a more descriptive account might be presented to the participant who could fail to recognise their own story (Morse, 1998; Morse *et al.*, 2008; Seale, 1999f). Lay participants might also fail to understand scientific language (Seale, 1999f). In this instance, it might have caused distress to participants to be reminded in detail of what they said during interviews about their experience of cancer.

While a variety of different criteria exist regarding what constitutes a high ‘quality’ grounded theory study, Birks and Mills (2011) put forward three useful key factors; *researcher expertise* (researchers’ skill), *methodological congruence* (researcher’s philosophical position acknowledged, appropriateness of the design) and *procedural precision* (such as memo writing, laying an audit trail, using ‘essential’ grounded theory methods). In this study, attempts to maximise the quality of the grounded theory developed included the previously described use of reflexivity, memo writing, use of key grounded theory methods such as constant comparison, acknowledging an epistemological stance as well as attempting to enhance qualitative interview skills through listening skills training (see Discussion, chapter 8).

Chapter 5: Theory of Adjustment to Cancer in Young Adults

5.1 Introduction

This chapter firstly outlines the sample characteristics as well as the timing of the Time 1 and 2 interviews. This is followed by an outline of the theory of adjustment to cancer in young adulthood. The theory was firstly developed from the interviews with testicular cancer survivors, and was further refined when analysing the Hodgkin lymphoma sample. The overall theory, presented below, is relevant to young adult cancer survivors with testicular cancer and Hodgkin lymphoma, and potentially other cancers in young adults.

5.2 Sample

A total of 28 young adult cancer survivors including 10 Hodgkin lymphoma survivors and 18 testicular cancer survivors aged between 21-44 years (mean= 32.57 years, SD= 7.26) were recruited from three cancer centres in the South of England. Health professionals reported a 33% response rate (28/85) that varied between cancer centres (71%, 44% or 28%). A fourth cancer unit had a 0% response rate. Overall, of those patients invited to participate in the study, 5% (n=4) refused to take an information pack, and 60% (n=51) took an information pack but failed to respond and 2% responded initially (n=2). The response rate was similar for testicular cancer (33%) and Hodgkin lymphoma (32%) survivors. Interviews at Time 1 mostly took place in participants' homes (n=20), place of work (n=3), or in a public café (n=5). At Time 2 (n=20), the majority of participants were interviewed at home (n=19), or at work (n=1). In total, 48 interviews were conducted with patients (testicular cancer, n=32; Hodgkin lymphoma, n=16). A summary of the demographic characteristics of the whole sample is shown in Table 4.

Table 4: Summary of participants' demographic information

Participant (Time 1)	Demographics	Total Sample (n=28) N (%)	Testicular cancer sample (n=18) N (%)	Hodgkin lymphoma sample (n=10) N (%)
Gender				
Males		22 (79)	18 (100)	4 (40)
Females		6 (21)	0 (0)	6 (60)
Age (years)				
20-24		6 (21)	2 (11)	4 (40)
25-29		5 (18)	3 (17)	1 (10)
30-34		4 (14)	4 (22)	1 (10)
35-39		9 (32)	4 (22)	4 (40)
40-45		4 (14)	5 (28)	0 (0)
Highest Educational Qualification				
GCSE's		9 (30)	6 (33)	3 (30)
A-Level's		2 (7)	1 (6)	1 (10)
Bachelor University Degree		12 (44)	9 (50)	3 (30)
Postgraduate Qualification		5 (19)	2 (11)	3 (30)
Employment				
Full-time		16 (57)	12 (67)	4 (40)
Part-time		9 (32)	4 (22)	5 (50)
Unemployed		3 (11)	2 (11)	1 (10)
Marital status				
Married		14 (50)	9 (50)	5 (50)
In a relationship		8 (29)	4 (22)	4 (40)
Single		5 (18)	5 (28)	0 (0)
Divorced		1 (4)	0 (0)	1 (10)
Ethnicity				
White British		26 (93)	17 (94)	9 (90)
British- Other		1 (4)	0 (0)	1 (10)
British- Asian		1 (4)	1 (6)	0 (0)

Living Arrangements			
Live with partner/or children	21 (75)	13 (72)	7 (70)
Live with parents	4 (14)	3 (17)	1 (10)
Live alone	3 (11)	2 (11)	1 (10)
Live with friends	1 (4)	0 (0)	1 (10)
Initial Treatment*			
Orchidectomy alone	6 (21)	6 (33)	0 (0)
Orchidectomy + adjuvant treatment	12 (43)	12 (67)	0 (0)
Chemotherapy alone	7 (25)	(0)	7 (10)
Chemotherapy + radiotherapy	1 (4)	(0)	1 (10)
Chemotherapy + surgery	2 (7)	(0)	2 (20)

*At Time 1 interview

5.2.1 Testicular cancer survivors

Eighteen testicular cancer survivors aged 22 - 44 years (mean= 34.11 years, SD= 7.03) were recruited. Eight participants were childless and 10 had children already, of whom the majority (n=8) had no desire for more children. Participants were employed in a variety of occupations including: military personnel, self-employed business owner, manual labourer, manager, driver, administrator and government worker. Men's treatment pathways varied (see Figure 1), as three participants were diagnosed with a recurrence of testicular cancer and received further treatment. Two of these men were interviewed at Time 1 after they had completed treatment for a recurrence, and 1 participant was diagnosed and treated for a recurrence between Time 1 and 2 interviews.

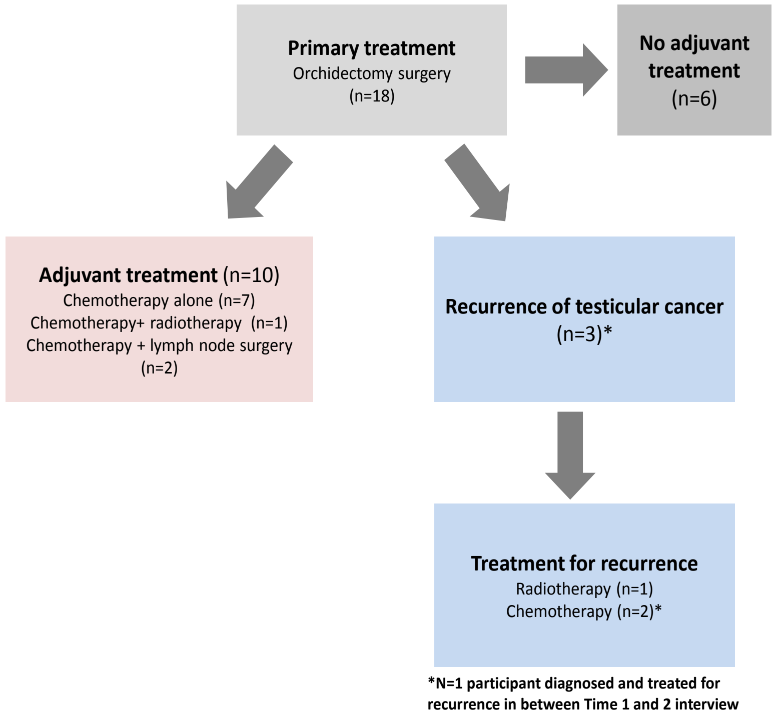

Figure 1: Flow diagram of testicular cancer participant's treatment pathways

5.2.2 Hodgkin lymphoma survivors

Ten Hodgkin lymphoma survivors aged between 21-39 years (mean=29.80 years, SD=7.19) were recruited. By Time 2, all participants were partnered, as the only single participant at Time 1 had developed a new relationship. Four participants were childless, three participants had one child, and the remaining three participants had two children, with four participants stating they had no current wish for more children. Participants were employed in occupations including self-employed business owner, domestic cleaner, teaching assistant, manager, care-home assistant, charity worker, shop assistant and receptionist.

5.3 Timing of interviews

Most Time 1 interviews were conducted around two months after treatment completion (range 3-16 weeks). The timing of the interviews in relation to treatment completion varied due to the work or personal commitments of the participants and when invitation packs were issued by cancer centres. Time 2 interviews were usually completed 7 months after Time 1 (range 6-11 months). One Time 2 interview was substantially delayed due to treatment received for relapsed Hodgkin lymphoma.

Fifteen participants with testicular cancer were invited for Time 2 and while all initially agreed to be interviewed a second time, only 14 were interviewed. The other three participants were not invited for Time 2 as data sufficiency was reached after re-interviewing 14 men. Time 2 interviews were conducted with six patients with Hodgkin lymphoma. Of the seven patients invited for Time 2 interview, only one patient was unable to be interviewed again. Due to time restrictions of the PhD, the last three Hodgkin lymphoma patients were not re-interviewed (see Table 5). Overall, the response rate to Time 2 interviews was 91%.

Table 5: Time 2 participants' characteristics

Time 2 participants	**Testicular cancer patients** (n=18) N (%)	**Hodgkin lymphoma patients** (n=10) N (%)
Male	14 (78)	2 (20)
Female	n/a	4 (40)
Total	14 (78)	6 (60)

5.4 Dismantling the current and future threats of cancer: a theory of the process of psychosocial adjustment to cancer in young adulthood

A theory (Figure 2) was constructed to explain the processes involved in positive psychosocial adjustment to cancer in young adults and to identify the responses that led participants to struggle to adjust in the year following treatment. A diagnosis of cancer in young adulthood is a shocking, disorientating and disruptive experience, which challenges assumptions about many aspects of life. For young adults, the key challenges involved in psychosocial adjustment are managing the current and future threats posed by the disease to the following key areas: life trajectory and life stage goals, the body and appearance, self and identity, psychological and physical wellbeing and relationships. To manage these threats, individuals must draw on both internal and external resources enabling them to *dismantle the present and future threats of cancer,* which was the core category of the theory. Positive adjustment entails two key transitions: *gaining a sense of perspective over the threats of cancer* (Transition 1) which relates to adjusting to diagnosis and treatment, and *striving to get on with life and restore normality* (Transition 2) which concerns post treatment challenges or threats to the future. These collectively comprised six processes:

Firstly, adjustment involves appraising or weighing up the significance of cancer (*process 1*). This involves resolving the mismatch between prior assumptions about cancer and the actual experience, often noted for its brevity and surrealism. This may lead to minimisation of the significance of cancer. Maintaining a positive sense of the meaning derived from experiencing cancer also contributes to gaining a sense of illness coherence, which may be particularly important for those for whom cancer treatment was more disruptive. The process of positive reframing (*process 2*) further helps to cognitively dismantle the threats of cancer. This is facilitated by the sub-processes of holding onto positive illness beliefs and making social and intrapersonal comparisons with other cancer patients perceived as worse off. Holding perceptions of cancer as a relatively acute, curable and specific cancer, rather than as a generalised disease helps the reframing process, and the ability to defend positive perceptions against negative societal views of cancer. Taking an active approach to overcoming the threats (*process 3*) involves the utilisation of external resources and support, for example one-on-one peer support with other survivors or disclosing and reflecting on their feelings and concerns with significant others. Using these and other resources help individuals to be proactive in managing their health and to regain a sense of control. Collectively, these three processes enable the transition to a new ***sense of perspective over the threats of cancer*** (Transition 1).

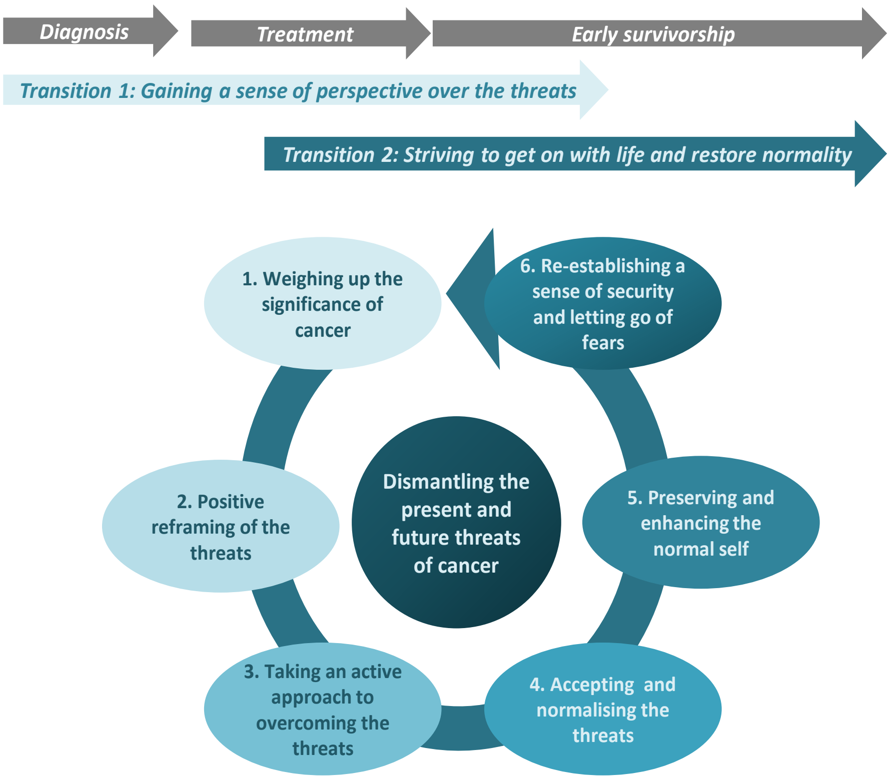

Figure 2: A theory of positive psychosocial adjustment: 'Dismantling the present and future threats of cancer (abridged version)

The transition of ***striving to get on with life and restore normality*** (Transition 2) is also vital in enabling individuals to dismantle the perceived threats to their future, to refocus their lives away from the threat of disease and to 'close the chapter' of cancer. Firstly, actively accepting and normalising the threats of cancer (*process 4*) facilitates this return to normality. This involves accepting and normalising the timing of cancer in young adulthood as well as changes in their body and appearance.

Preserving and enhancing the normal self (*process 5*) is facilitated by resisting illness centrality and a ‘cancer survivor’ identity which helps to defend against the threat to identity and to support the maintenance of a normal identity throughout the experience. Finally, re-establishing a sense of security and letting go of fears or threats (*process 6*), for example, towards future parenthood or a recurrence of cancer, enables young adults to get on with life. Holding onto the anchors of security (relationships, parenthood status, work and confidence in health professionals) also facilitates positive adjustment following treatment completion as does accepting a more precarious future and living more ‘in the present’. Collectively, these three processes enabled participants to transition to *getting on with life and a restored sense of normality* (Transition 2) in the year following treatment completion, and dismantle the perceived threats to participants’ future lives.

Overall, these six aforementioned processes culminate in a sense of acceptance, coherence, perspective, normality and security over the threats of cancer, as well as a sense of positive meaning from the event, which were key dimensions of positive adjustment. These are not definitive ‘end points’ in adjustment but indicate the positive transitions that occur as young adults move from a state of distress and disorientation around diagnosis and treatment, and from a state of uncertainty and insecurity around treatment completion. Contextual influences, such as relationship or parenthood status, disease or treatment variables may affect the magnitude of the threats of cancer. Figure 3 presents the theory with both processes as well as sub-processes involved in adjustment.

Not all of the participants in this study adjusted positively to their cancer experience. The core category involved in a negative adjustment trajectory was *holding onto the threats of cancer.* The two key transitions in negative adjustment that led them to struggle to adjust in the year following treatment were *losing a sense of perspective over the threats of cancer* (Transition 1) and *struggling to achieve a sense of normality after cancer* (Transition 2). Transition 1 involved three processes: struggling to gain a sense of coherence and appraising as a major event, holding negative illness perceptions and taking a generalised view of cancer and adopting a stoical and silent approach. Transition 2 also involved three processes: ambivalent acceptance of cancer and struggling to accept the threats, struggling to defend against threats to identity, losing a sense of security after treatment completion and ruminating on fears. These processes manifest in a sense of isolation, disrupted self-identity, insecurity, fear, distress and low self-confidence. Figure 4 displays the positive and negative adjustment trajectories for young adults. This model highlights the negative adjustment ‘layer’ in the theory of psychosocial adjustment, as the negative adjustment processes may oppose and block the positive adjustment processes.

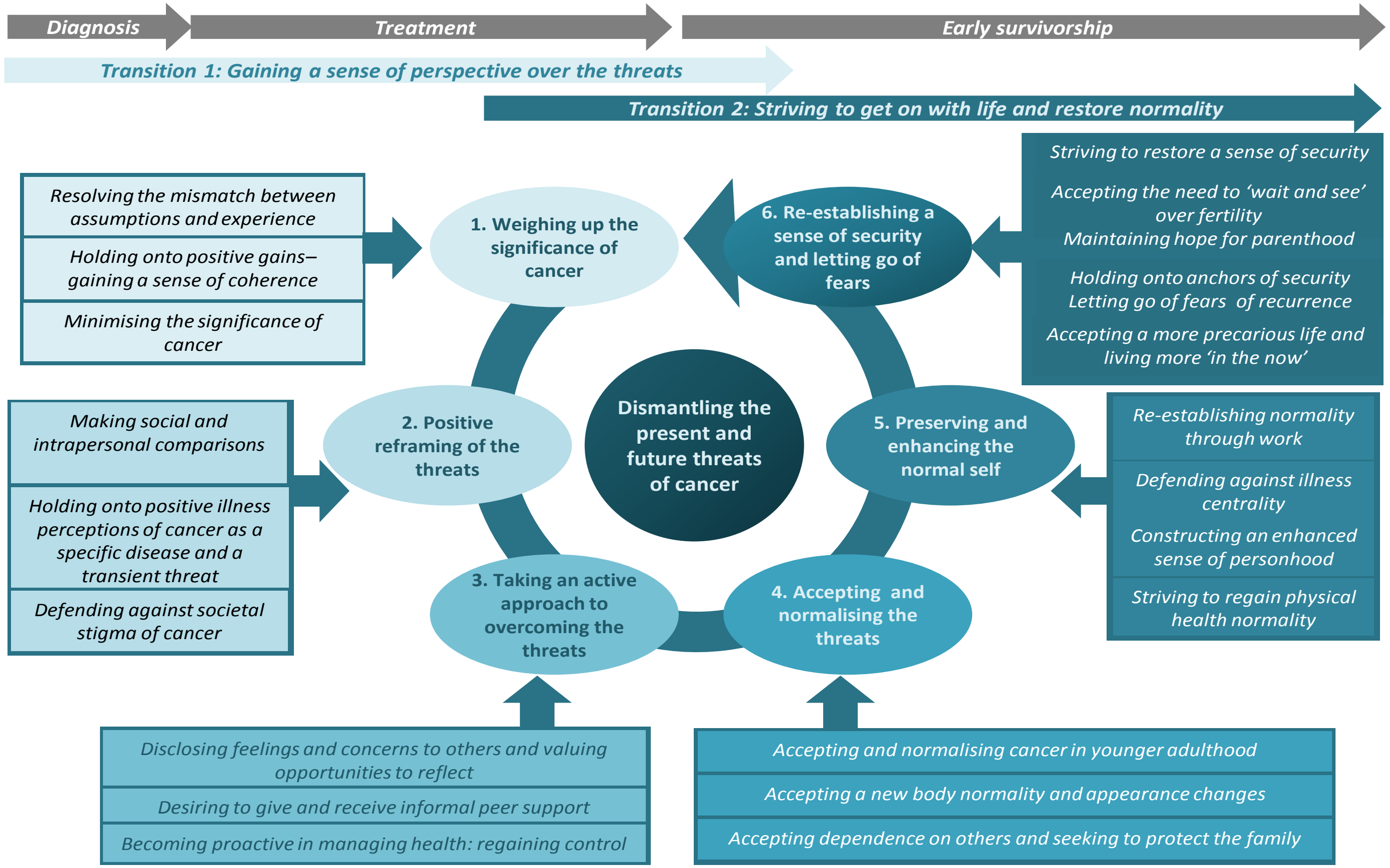

Figure 3: A theory of positive psychosocial adjustment: 'Dismantling the present and future threats of cancer'

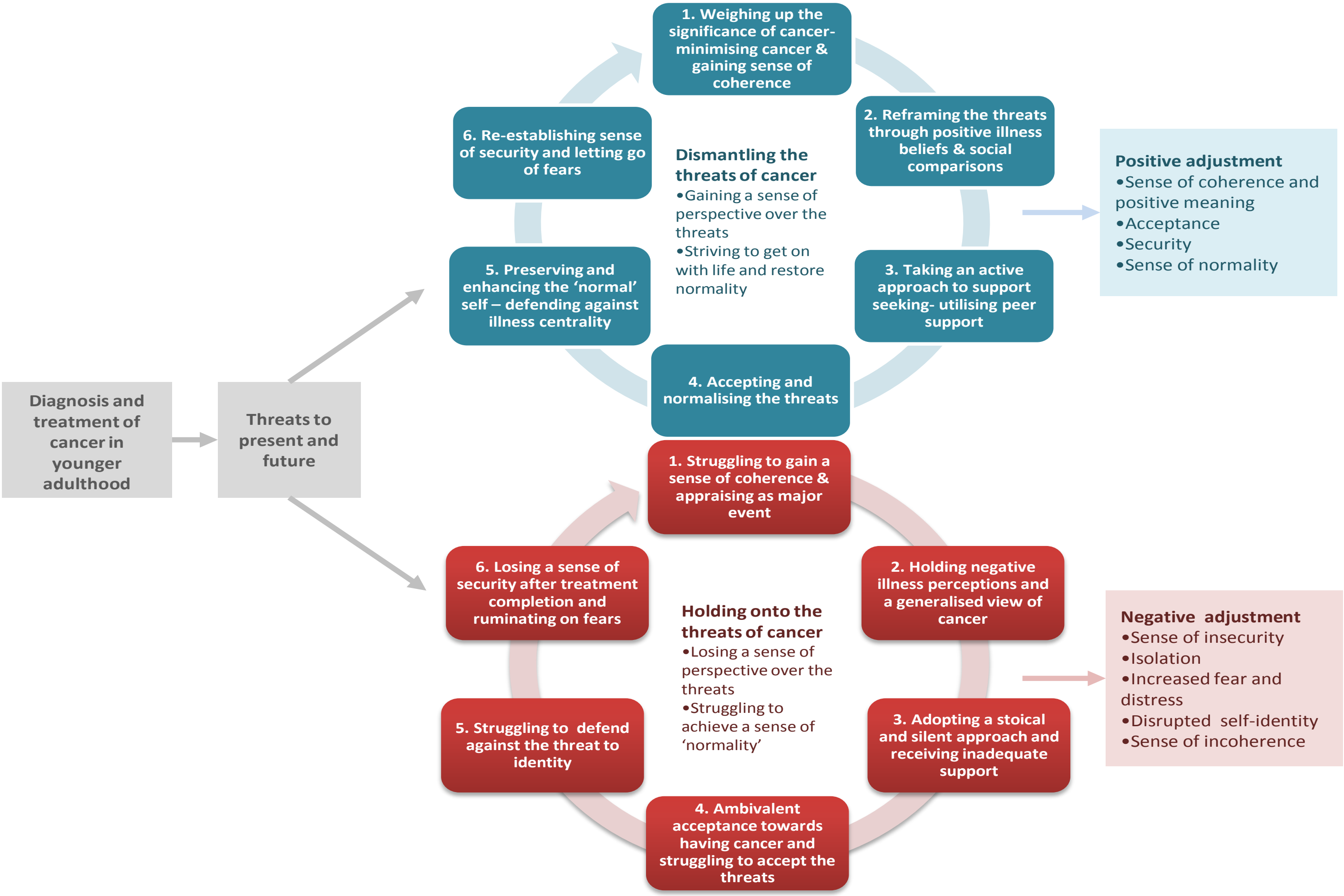

Figure 4: Positive and negative adjustment to cancer

Chapter 6: Adjustment in Young Adults with Testicular Cancer

6.1 Introduction

This chapter will begin with an outline of how the Time 1 and 2 interview data will be presented, as well as the site specific data. The experiences of men with testicular cancer will then be presented using the framework of the theory of adjustment to cancer set out in the previous chapter. Figure 5 illustrates the theory relevant to the sample of testicular cancer survivors (highlighted in bold). A negative case example of a testicular cancer survivor is also presented.

6.2 Presentation of Time 1 and 2 interview data

The majority of participants appeared positively adjusted soon after treatment completion, and by Time 2 interviews, many felt that they were successfully getting on with life following the experience with few or no issues. Time 1 and Time 2 interviews are, therefore, presented simultaneously as there were few differences across time, so data from Time 2 interviews added further richness and depth to the analysis. The key processes identified in the theory were also consistent across Time 1 and 2 interviews. In the sample as a whole, most participants achieved positive adjustment with some struggling to adjust to specific areas. Adjustment patterns over time appeared to be stable in most participants with a few exceptions, in terms of increasing distress and negative adjustment. Where longitudinal differences were detected, they are presented throughout the findings chapters. A negative case example is presented at the end of part-one, which illustrates the processes involved in negative adjustment, based on a participant with testicular cancer.

6.3 Presentation of the site-specific interview data

The analysis from the interviews with testicular cancer survivors are presented first, followed by the Hodgkin lymphoma survivors (Chapter 7). The data for both samples are presented in the framework of the theory. The separate presentation of the two groups of cancer survivors allows for the site specific issues to be highlighted, as some of the sub-processes could vary between these different samples of survivors (see Figures 5 and 6). Presenting the data separately allows for the complexity of adjustment to two different types of tumours to be highlighted, which was deemed important in light of the differences in treatment regimens and symptom severity between the two patient groups. The Hodgkin lymphoma sample also included female participants, and all participants in this sample had experienced many months of intensive chemotherapy treatment. Due to these differences in treatment experiences, the unmet care and information needs of the Hodgkin lymphoma sample are more pronounced than the sample of men with testicular cancer. The model of the theory of adjustment, with cancer site specific modifications (mostly variations in sub processes) is again presented before each section on the two samples. The sub processes relevant to each patient group are highlighted in Figures 5 and 6.

Key – Abbreviations

T1 – Time 1 interview
T2 – Time 2 interview
Surgery – Treated with surgery alone
Surgery + C/R – Treated with surgery and chemotherapy/radiotherapy
Chemo - Treated with chemotherapy alone
R – Treated with radiotherapy
SCT- Stem cell transplant
* - Treated for a recurrence or relapsed disease
** - Treated for advanced disease

6.4 Interviews with testicular cancer survivors

Figure 5 provides an illustration of the theory of adjustment relevant to men with testicular cancer. Sub processes relevant to this patient group are highlighted in bold (with an asterisk).

Transition 1: Gaining a sense of perspective over the threats of cancer

The transition of *gaining a sense of perspective* over the threats of testicular cancer was a vital process that involved several sub-processes. The majority of men progressed through this transition quickly and in a positive way, following the disorientation of diagnosis and treatment.

Process 1. Weighing up the significance of cancer

During early survivorship, men engaged in a process of weighing up the significance of testicular cancer, often appraising it as a minor disruptive event in their lives. The significance of testicular cancer was considered in terms of both the degree of perceived disruption and meaningfulness to their lives, and this appraisal process often led to a greater sense of coherence over the experience.

1.1 Resolving the mismatch between assumptions and experience

Gaining a sense of perspective was firstly facilitated by the sub-process of resolving the mismatch between assumptions and experience in terms of men's assumptions towards the disease and treatment. Firstly, receiving a diagnosis of testicular cancer was an unpleasant shock, often evoking notions of cancer as a life-threatening disease, which heightened fear and uncertainty.

> '*It does really knock you out of your shoes when you first get told cos you're just not expecting that. It is difficult at first'* (P12, T2, 37 yrs, Married, Surgery)

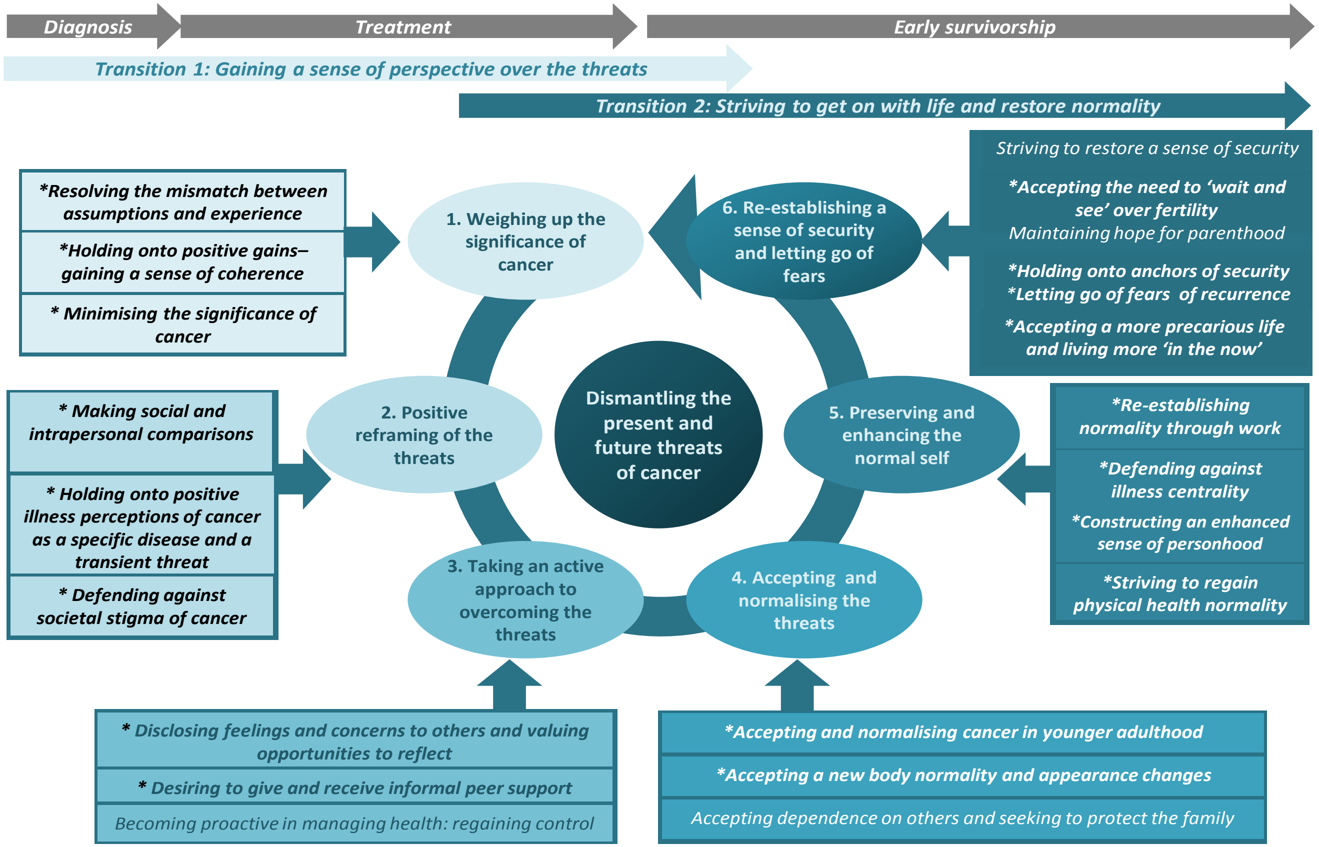

Figure 5: A theory of positive psychosocial adjustment: 'Dismantling the present and future threats of cancer' (specific to men with testicular cancer)

The quick onset of surgery following diagnosis was attributed as a positive factor in helping them adjust quickly, as men could feel initially fearful before surgery. Men who received adjuvant treatment (chemotherapy and/or radiotherapy), which often ranged from several weeks to months in duration, could encounter difficulties with treatment side effects, including nausea, fatigue, infections and weight gain. Some admitted difficulties with having life 'on hold' and feeling restricted and isolated during this time. However, men discussed a vast discrepancy between their initial assumptions and the actual experience of treatment and recovery, as they often felt that the experience of testicular cancer was not as bad as they expected and feared. At diagnosis, men recalled being more fearful of chemotherapy than of the disease itself, expressing relief when they only required surgery and no adjuvant treatment. Some participants who had received surgery alone often felt they had '*gotten away with it'*.

> *[Interviewer: Was it [treatment] as bad as you thought it might be?]*
>
> *'I don't think so. I think there were probably a handful of days that were as bad as I thought it might be feeling physically, and I thought that that is what it would be like the whole time through'* (P25, T1, 30 yrs, Single, Surgery+C)

Moving on from an initial state of shock and fear involved relinquishing assumptions and cultural connotations around cancer and cancer treatment, as they were often felt not to be applicable to the experience of testicular cancer. An ongoing sense of ambivalence over the disease experience could result if men grappled with resolving this discrepancy.

> *'I just felt like I had an operation, it didn't feel what everybody tells you what cancer's like'* (P2, T2, 24 yrs, single, Surgery+C*)
>
> '*Although you see the sort of headlines in the paper and you go and think perhaps I'm just not taking it seriously enough I'm not too sure which might seem strange, perhaps I'm in denial, you never know'* (P9, T1, 44 yrs, Married, Surgery+C).

1.2 Minimising the significance of cancer

Following successful treatment, men often evaluated testicular cancer as a significant yet relatively minor biographical event *('in the scheme of things it's quite a minor isn't it?'* P8, T1), which was not particularly life changing and resulted in relatively little disruption to their current or projected future lives. This was influenced by men's experience of symptoms and treatment as having a minimal impact, as well as the brevity of the experience.

> '*it's just one of these things that you can either sit there and mope about it or you can just accept it, and then weigh it all up and realise that actually, it's not that bad, it could be a lot worse, so you've been pretty lucky'* (P23, T1, 30 yrs, In a relationship, Surgery+C)

On reflection, some men talked about perceiving testicular cancer as one of life's challenges to overcome, rather than a major threat.

> '*So it is a significant event but not a life changing event…It's not a major event, I think yeah, not a major event at all, it was a challenge, it was a situation I was put in that I had to deal with and has been dealt with like so many others…I've always quite enjoyed a challenge,*

> *not that I would have really wished for this, but it didn't really it hasn't with hindsight set me back, I've continued to move forwards'* (P15, T1, 40 yrs, Married, Surgery)

Some described difficulty expressing this view with spouses or family members over fears of appearing '*flippant*' (P9) and thus devaluing the emotional distress and psychosocial impact on others.

> *'A lot of people have said you've been through a traumatic thing, you're this and you're that, and you've done this, and.. without sounding big headed about it, it's not that big a deal…I don't think it's been bad at all, but I think it's the word isn't it, it's cancer, and you know it hit a lot of my mates..*' (P16, T1, 38 yrs, Married, Surgery)

Participants' treatment or disease status did not appear to influence the degree to which they perceived testicular cancer as either a major or minor biographical event. In fact, minimising the significance of cancer and perceiving it as a challenge appeared helpful at increasing participants' sense of mastery and control over the disease. P20, who received extensive treatment for advanced disease did not perceive the event as a major one.

> '*Testicular cancer was just something that I had, like I've still, technically I've still got it, not been given the all clear, but like it was just an obstacle I had to get around, it was never, never anything that was going to shut me down or stop, so I didn't see it, I don't see it as a major thing'* (P20, T1, 22 yrs, Single, Surgery+C**)

1.3 Holding onto positive gains – gaining a sense of coherence

Testicular cancer had a positive transformative effect on some men, particularly to their outlook towards life, although some felt changes had been minimal. When the disease was perceived as a more major biographical event, participants seemed to more strongly derive and hold on to positive gains from the experience. Men often felt that going through the experience had led to strengthened relationships and emotional closeness with others and reported a greater appreciation for their lives and families.

> '*It's a realisation of what could have been and looking forward now to what's in front of you and enjoying everything that you have got, whereas before we would probably do nothing and now we're actually saying well right, so in some ways it's brought family closer'* (P1, T1, 36 yrs, Married, Surgery+R)

These positive evaluations developed over time as men made sense of the experience of diagnosis and treatment, and holding on to these positive gains helped them to reconcile and let go of negative thoughts and fears, refocus their lives and strive towards the future.

> *'just keeping positive….when I go [playing sport] you just build yourself up with positive thoughts and you come back and the next thing you know the weeks gone past… good news…. next six months'* (P1, T1, 36 yrs, Married, Surgery+R*)

The shock and realisation of the threat of mortality was often reappraised as an important '*wake-up call'* (P17) helping participants to avoid getting '*stuck in a rut'* (P1), prompting them to actively engage more with significant others. The positive gains culminated in the development of a sense of coherence over the illness, perceiving it as a meaningful biographical event.

> *‘almost the benefit of having cancer it makes you re-evaluate your whole life and your friendships and the way you are and your job, cos before that you just tick along in a nice little way, you like to think you don’t take it for granted but I think we all do, so sometimes a boot up the backside…’* (P18, T1, 44 yrs, Single, Surgery+R+C)

Drawing upon positive meaning was particularly salient for men who were single, childless or lived alone, who had not already achieved typical milestones of masculinity. The ability to derive positive gains seemed to be regardless of the type of treatment men had received, as one participant (P12) who underwent surgery alone even went as far as to say that every area of his life was improved following testicular cancer.

Process 2. Positive reframing of the threats of cancer

The transition to gaining a sense of perspective was also facilitated by the process of positive reframing of the threats of testicular cancer through social and intrapersonal comparisons and holding positive illness perceptions. This was maintained by the sub-process of defending against societal stigma of cancer.

2.1 Making social and intrapersonal comparisons

The process of making meaningful social and intrapersonal comparisons helped reframe testicular cancer in a more positive and less threatening way. Making intrapersonal comparisons involved comparing their experience to other life threatening events in their lives.

> '*this is quite potentially odd, but it could be just the person I am, the job I do, but I've never really been scared of the issue, it's a shock, but I don't think I was ever worried, I don't think I was really scared of what the future held, my job takes me to some dangerous situations, I've been in some dangerous situations, I've seen death'* (P15, T2, 40 yrs, Married, Surgery)

The most commonly used comparisons appeared to be downward social comparisons, as participants compared their situation to those worse off, usually to other cancer patients or people with chronic diseases. This helped to reframe their experience of treatment and put it into perspective.

> *'I think compared to some people that has to go through loads and loads of chemo and stuff, I only had to have two lots, when I was in the hospital there was a bloke in there, he had it six times.. I expect that drags you right down'* (P7, T2, 43 yrs, In a Relationship, Surgery+C)

The level of the threat of testicular cancer was appraised in relation to the key milestones' in men's lives, as some felt they had already achieved key milestones, so this lessened the threat of the disease. Participants who were married with children felt that the impact of the disease would have been much worse if they were younger, unmarried and without children.

> *'I think if I was on my own and I didn't have kids and a wife I might have thought differently about the treatment and what it's done to me, but because I've got a wife and kids I'm all settled down, that side of things didn't really worry me it's more of how they were gonna feel'* (P5, T1, 28 yrs, Married, Surgery+C)

Conversely, men who had not reached these milestones could perceive their lack of commitments or responsibilities as an advantage, when making comparisons to men who had. Therefore, the process of making comparisons appeared more important than their actual life stage, as this helped to dismantle the threat of disease through gaining a sense of perspective.

> *'looking at it from someone else's point of view I don't know if that might be a bit difficult, maybe people with kids and things like that, where there is a lot more complexity in their lives, whereas for me it was very easy, I'm pretty much, in my early twenties I don't really have any responsibilities, I don't have a girlfriend, I don't have kids, it's really just my parents and my friends and that was it'* (P2, T1, 24 yrs, Single, Surgery)

Men also used upward social comparisons to role models or those better off, such as other testicular cancer survivors known to them who were back to normality or coping well, which was a reassurance. This process seemed useful for reducing the threat of testicular cancer to their *future lives*, whereas downward social comparisons seemed more useful during treatment and early recovery for dismantling the threat to their *current lives*. The use of parallel comparisons with others in a similar position to them also helped normalise the disease experience.

2.2 Holding onto positive illness perceptions of cancer as a specific disease and a transient threat

The process of holding onto positive illness perceptions and embracing the positive discourse surrounding the disease appeared vital for dismantling the threat to psychological wellbeing. Men admitted, however, that holding onto positive illness beliefs was a lot harder during psychologically challenging periods, such as during treatment or waiting for initial results.

> '*The survival rates are so high that the likelihood is that your gonna come out fine, you don't really think that at the time, because your mind wanders'* (P14, T2, 31 yrs, Married, Surgery+C*)

Positive illness perceptions commonly referred to the high rates of successful treatment, acute nature and shorter treatment duration and severity of testicular cancer.

> *'It definitely made it easier to deal with, because such a high cure rate that I could quite happily say to myself whilst I was going through it all, yes, I do currently have cancer, but chances are in nine, eight, seven weeks I won't, which is brilliant. If it were something else where it was considerably lower cure rate or we start talking about remission rather than cure, probably would have made*

> *that a lot more difficult to deal with'* (P25, T1, 30 yrs, Single, Surgery+C)

Having an optimistic personality was attributed by some participants as a contributing factor to these perceptions. Holding strong positive illness beliefs could lead to strategies of avoiding information which challenged these beliefs, such as negative stories on the internet or even avoidance of medical information by one participant with advanced disease (P20). This helped participants to defend against these beliefs.

> '*it doesn't matter what happened to you [other patients], it's me and it ain't going to happen to me…so it was something that was never going to happen, so I didn't want to read about it [online]'* (P20, T1, 22 yrs, Single, Surgery+C**)

At diagnosis, reassurance from health professionals helped to shape positive perceptions of testicular cancer as '*the best one to get'* (P7, T1). Differentiating between testicular cancer and other types of cancer and perceiving it as a specific and distinct disease appeared helpful. Men often felt that having cancer in the testicles was the best place to get it, and so could compartmentalise the threat as they felt that the cancer was compartmentalised as well.

> *'from what the doctors' were telling me it's the best place for a man to get it, so it sounds stupid but I was glad I got it there rather than in my lymph nodes or bowel, it's the best place for a man to get it, so the word 'cancer' is horrible but for a man to get it there it was sort of a plus thing'* (P5, T1, 28 yrs, Married, Surgery+C)

> ‘*Testicular cancer is not really cancer, it’s like baby cancer’* (P17, T1, 27 yrs, Single, Surgery+C)

In comparison, taking a generalised view seemed to increase feelings of susceptibility to having cancer again in another part of the body. Conversely, successful adjustment was facilitated by perceptions of the disease as a transient threat or a ‘*blip’*, rather than an enduring threat. Over time, most participants received good news that they were ‘all clear’, apart from P2 who was diagnosed with a recurrence. Continually being given positive news created an understanding of testicular cancer as an acute and curable illness that was likely to pose no long term threat. Conversely, perceiving the threat as enduring or as a chronic illness meant participants struggled to find normality. This was particularly evident in P2 who had a recurrence, and the uncertain trajectory of the future meant the threat felt enduring as he had been told he may need more treatment.

> *‘Yesterday was one of the first days when yeah I really dwelt on a few things and thought, this is going be a never ending process’* (P2, T2, 24 yrs, Single, Surgery+C*)

2.3 Defending against societal stigma of cancer

Positive perceptions could be threatened by what was felt to be distorted and stigmatising cultural and societal views of cancer, especially generalised views of the disease (*‘it does have a stigma against it’* P15, T1). As a result, some men reported having difficulties disclosing their cancer status to others. Some men chose to delay disclosure to family members due to the anticipated ‘*over reaction’* to the diagnosis, which was deemed disproportionate to the reality of the disease and an unwanted burden. They also sought to protect others from distress. Participants often had to reiterate their positive perceptions of the disease to others as a way of conveying an accurate view of the threat. Some men felt like a '*fraud*' (P23) cancer patient in the face of much public sympathy.

> '*That's one of the things that I've found difficult to get my head around is when you tell people you have cancer, or when I told people I had testicular cancer, the word they latch onto is cancer.. all they hear is 'I have testicular [small voice] cancer [loud voice]'* (P23, T1, 30 yrs, In a Relationship, Surgery+C)

In fact, issues surrounding disclosure and dealing with other's reactions to the diagnosis were sometimes reported as a particularly challenging aspect of having testicular cancer with some men choosing to avoid telling many others at all. Other participants felt they should tell everyone, yet struggled with repeated disclosure and having to deal with the emotional reactions of others.

> '*That is probably the hardest bit telling people, but only cos people have this funny view of cancer being horrific'* (P8, T1, 33 yrs, Married, Surgery+C)

Several reported peers who were unable to cope with their diagnosis and so provided inadequate support or even abandoned the friendship. This could sometimes hinder men's attempts to seek out support and solidarity from 'normal' peers.

> *'I did lose I'd say half the people I thought were quite close'* (P17, T2, 27 yrs, Single, Surgery+C)

Humour was often used as a disarming tool during social situations with peers as a way of defending against the stigma of cancer and of being treated as 'different'. Some actively used humour when initially telling friends or colleagues about testicular cancer, in order to reduce the concerns and emotional reactions of others, and thus reframe the threat to others in their social and working environment.

> '*when they saw that I could talk about it and joke about it so they [colleagues] were a lot more relaxed, and then they could joke about it to and then the banter could start and that was all really good'* (P23, T1, 30 yrs, In a Relationship, Surgery+C)

> '*I sent a text to all of my [colleagues] to go and say '[Tony] the testicle has left the building...I wasn't worried about it. I prefer to just be upfront and tell people this is what it is, they make of it what they make of it, at least they know rather than people sort of whispering and sort of coming to false conclusions'* (P9, T1, 44 yrs, Married, Surgery+C)

Overall, men's defences against societal misconceptions of testicular cancer helped to maintain their positive perceptions of testicular cancer and so reframe the disease as less threatening.

Process 3. Taking an active approach to overcoming the threats –utilising external resources and support

Throughout the illness trajectory, it seemed that men's ability to utilise the external support available to them was important in promoting adjustment and differentiated between men who seemed to adjust more readily and those who were struggling. Men with coping styles of active support seeking and emotional disclosure fared better than those who were stoical and concealed their feelings and concerns.

3.1 Disclosing feelings and concerns to others and valuing opportunities to reflect

Men felt strongly that testicular cancer was often more disruptive and distressing for their spouses and close family members. The accumulation of practical and emotional difficulties over treatment could mean the end of treatment was a difficult transition, as men reported spouses with anxiety and stress-related issues. Men emphasised the need to 'stay strong' for others so as not to increase the burden on them.

> *'[wife] was just trying to hold it together for [child] and myself and then when she realised that it was not all over for me but when I'd come through the second lot of chemo and I was started to get back to normal, that's when it hit her, yeah it was very hard on her .. cos she suffered a lot from anxiety and stress and panic attacks after I'd gone through it all it suddenly all hit her, and she's had a lot of help'* (P16, T2, 38 yrs, Married, Surgery+C)

Partnered men often regarded the practical and emotional support of their spouse as the most important aspect helping them adjust to and cope with cancer. For single men, parents were often the key source of support. Over time, men increasingly adopted more active approaches to eliciting this support, in terms of being more open to disclosing their feelings. In particular, having opportunities to reflect on their experience seemed to be an important process in helping men to make sense, gain a sense of perspective and feel supported. Some commented that the research interviews were helpful, as men felt that talking about cancer in an everyday setting sometimes needed to be sanctioned by others (‘*it's been nice to have a chat to somebody*’ P18, T2).

> *‘I've found this [research interview] interesting, not just interesting but also helpful, I remember thinking a lot about my experience after you left last time and I'm sure I'll do the same this time’* (P14, T2, 31 yrs, Married, Surgey+C*)
>
> *‘It was actually nice to talk to someone today and go blurb, if I said this stuff to anyone else they'd go nuts..’* (P10, T1, 41 yrs, Married, Surgery)

During diagnosis and treatment, some men highly valued contact with the Clinical Nurse Specialist (CNS), particularly for help with addressing psychosocial issues. Others seemed reluctant to utilise their support or were unsure about their role, and those treated with surgery alone were generally less in need of nurse support. CNS's were also felt to be a vital source of support for their spouses and parents. Although men were often reluctant to call their CNS, they highly valued the offer of telephone support once treatment was over should they need it.

> *'[wife] will phone [CNS] and sort things with [CNS] cos I'm a man I suppose I don't really'* (P8, T2, 33 years, Married, Surgery+C)
>
> *'I'm not one to really feel that I need to hold someone's hand the whole time, in fact probably the opposite, going to hospitals all the time for this that and the other is probably a bit of a burden on me, but I'd certainly feel like the support tails off but it's great to have that safety net that I could just give them a call [CNS] whenever, it's quite reassuring'* (P2, T1, 24 yrs, single, Surgery)

For some men, attempts to protect their spouse or parents' feelings could mean emotional disclosure was compromised, especially in men with a more rigid adherence to 'traditional' masculine values such as stoicism, independence and autonomy. This also seemed to constrict men's willingness to seek support from health professionals, as well as peers ('*I stick to myself and keep plodding'* P1, T2). This coping style led to a sense of isolation from family members and sense of abandonment from health professionals. Several participants wanted signposting for ongoing treatment effects, such as fatigue, and could feel stuck between primary and secondary care clinicians who both seemed unable to help. This was impacted by the quality of the relationship with the clinician as these men all reported a lack of rapport during consultations.

> '*You just want someone to go, if you've got a problem go to your GP, or if not you phone this person, any questions phone this person,*

> *that would be the only thing, [health professionals'] just kind of go 'well you're fine you're fine'* (P10, T1, 41 yrs, Married, Surgery)

This coping style of stoicism and emotional concealment was evident in several other participants, however by Time 2; most participants seemed to have adopted a more active approach to emotional support seeking. Some men, however, seemed to have a more flexible approach in their adherence to these values of masculinity, and felt they were more open in talking to health professionals and others ('*Maybe I'm more modern than most men?'* P2, T1). This seemed particularly the case in younger and more educated men in this sample, who had more adaptable models of masculinity.

3.2 Desiring to give and receive informal peer support

Men found talking to others who had also experienced cancer particularly useful, as many knew other cancer patients through their social network or through their time in hospital ('*you can't bottle it all up'* P23, T1). Although instead of viewing these conversations as support as such, men emphasised the importance of talking *informally* to others, thus maintaining masculine values of self-reliance. Men particularly valued one-on-one informal peer support with other testicular cancer or male cancer survivors. Importantly, while men valued *receiving* peer support, men seemed to prefer talking about *giving* peer support and often had a strong desire to share testicular cancer 'expert' knowledge, rather than being the one in need of support themselves. Offering their knowledge as a peer mentor seemed to increase feelings of self-esteem and confidence.

> *'I had a chat to him [testicular cancer patient] and said, they say everyone's different, and that's true, but this is what the last seven weeks have been like for me, any questions, here's my number, give me a shout.. He didn't call…I mean if someone had said that to me I probably wouldn't have called…. well it would have been most useful before it started, either in the gap between [diagnosis and treatment], or on the first day or two of inpatient treatment. It would have been useful for me if there had been exactly like I was for that chap, someone coming to the end just as I was starting, just kind of there…getting an opportunity to speak to someone who'd been through it just before you start'* (P25, T1, 30 yrs, Single, Surgery+C)

Peer support from 'normal' and 'cancer' peers seemed particularly important for single men, especially if they lived alone, as well as men who had a recurrence or extensive treatment. Some married men felt unable to share their fears with their spouse so also expressed this need. P1, for instance, valued sharing his experience with others who had also experienced cancer that were known to him through his existing social network.

> *'It's quite good there's someone there to talk to, but because I've had it longer and mine came back, they [peer survivors] seem to come to me for the questions and answers scenario, so I just reassure them and tell them so yeah it's quite good, that there's somebody there to talk to than obviously my wife, cos sometimes it's not an easy thing to talk about'* (P1, T2, 36 yrs, Married, Surgery+R*)

During the initial stages of treatment, peer support helped to normalise the experience and reduce men's initial treatment concerns (‘*He [peer survivor] made me feel a lot better going into it’* P17, T1). This type of support also helped men gain a sense of perspective and shape realistic perceptions of testicular cancer.

> *‘I just think it just helped just reassure me, like I wasn't a nutter, or some weirdo, and you're not the only person, you won't ever be the only person who's gone through it, there are other people and they can help you out’* (P20, T1, 22 yrs, Single, Surgery+C**)

Once treatment was over, talking to peer survivors helped men better accept a state of ‘new normal’, if recovery took longer than expected. Talking to peer survivors was also valued as men felt they sometimes needed a ‘green light to talk’ about cancer.

> *‘It was a reassurance to know that you weren't just being a Muppet and it's gonna take a year or 18 months [to recover from fatigue], although I'd been told that previously I didn't accept it or want to accept it’* (P18, T1, 44 yrs, Single, Surgery+C+R)

Men who didn't have peer support felt it would have helped them dismantle their fears earlier, particularly their initial fears over how they would feel after treatment as well as thoughts around a threatened masculinity, body, psychological wellbeing and work life (‘*that would have been nice to have had a mentor’* P18, T2). It was also felt that peer support would have been particularly useful after diagnosis or during the initial stages of treatment, as a provider of experiential information on ‘what to expect’, and this could have shaped more realistic expectations.

> ‘*yeah you’ll be back at work you won’t feel any different, you’re not gonna have a high pitched squeaky voice, you’re still gonna have facial hair, you’ll be fine, you’ll be exactly the same, and if you didn’t’ tell anyone you’ve got it no-one would know, and it makes no difference at all, and that would have been great for me to have got someone telling you that’* (P12, T1, 37 yrs, In a Relationship, Surgery)

At Time 2 some men wanted to put the experience of testicular cancer in the past, so felt peer support was not needed at this point. Also, not all men valued or wanted contact with other peer survivors, preferring to utilise their own existing support network.

> *‘I don’t think I’m one for sort of ringing hands and all let’s compare our problems that are exactly the same, it’s not something that I find helps me, I understand how it would help other people, but I’d rather just talk to someone one on one necessarily who doesn’t have a clue on what’s going on.. that would do for me’* (P2, T2, 24 yrs, single, Surgery+C*)

Men emphasised the need for connections with cancer peers that were ideally something offered to them as part of their care, as having to seek out support was seen as challenging to masculine values.

> *'I remember saying at the time, the first diagnosis, that I really wanted to talk to someone and I didn't know who I could, and I don't know being a sort of a proud man you don't really wanna go online and do the extra work.. really it would have been at the time just be great, just go for a beer with someone who had actually been through that and could just give you an inclination…so sitting down with someone or speaking over the phone would have just been really helpful cos they would have given me their take on things… that real life sort of scenario'* (P14, T2, 31 yrs, Married, Surgey+C*)

The notion of attending a support group was often rejected outright as conflicting with masculine values ('*probably men will go down the pub won't they?'* P1, T1). Men also commonly rejected the idea of needing professional or formal psychological support, again, wanting informal contact. One participant expressed the need for *'someone to talk to, whose gonna listen and just give you time*' (P10, T1) who had medical knowledge and could help with ongoing issues, not discounting the idea of being in a group of peer survivors. Amongst those who stated that psychological support could be beneficial, there was still reluctance to seek out support, as this challenged hegemonic masculine ideals over wanting to cope independently. One participant who had a recurrence (P14) felt that counselling could be beneficial yet would be better accepted if it was part of the care package, or even suggested by a peer mentor in order to normalise help-seeking *('if [counselling] was all part of the package I would accept it a bit easier'* P14, T2).

Due to their initial fears and sometimes due to a lack of peer support, men sought information online regarding other men's experiences of testicular cancer. While some found official cancer charity websites useful for factual information, information on other men's experiences found through more unofficial chat forums were often perceived to be biased, overly negative and not representative of their experience. This could heighten men's fears and confusion and increase the threat of the disease *([online forum information]...it killed me for days, it was all horror stories*' P10, T1). Men often expressed frustration over the lack of experiential information which was congruent with their own experience, and desired more information that gave a more positive and realistic perspective of testicular cancer treatment and recovery.

> *'There's not a great deal [of information] that says oh it's actually quite easy…. maybe it might be nice to know that coming out the other side that it's actually alright and life goes on and you'll be back at work in 6 months or whatever as if nothing really happened..'* (P8, T2, 33 years, Married, Surgery+C)

Summary of key transition 1: Gaining a sense of perspective over the threats of cancer

To summarise, the aforementioned processes enabled positive adjustment to testicular cancer through *gaining a sense of perspective over the threats*. These processes helped men to dismantle the threats of cancer, particularly during the diagnosis and treatment phase, towards the body, life trajectory, relationships and masculine identity. These processes enabled men to make sense of the illness and cognitively and emotionally manage the disruption. Using active coping styles to elicit support from others led to feelings of belongingness and a sense of solidarity from knowing others ‘in the same boat’. Some men struggled more than others over time, and one participant in particular (P10) had not *gained a sense of perspective* by the end of the study (see negative case example p. 214). Poorer adjustment involved holding a generalised view of cancer, struggling to resolve the mismatch between assumptions and experience, as well as maintaining a stoical and silent approach.

Transition 2: Striving to get on with life and restore normality

The second key transition of *striving to get on with life and restore normality* appeared more challenging for men than Transition 1. For some men, testicular cancer was perceived as a largely historical event in their lives by Time 1 interview. Some men felt they had achieved normality, particularly if they had minimal physical or psychosocial effects (‘*life’s back to normal now’* P5, T2). While others felt they were getting closer to their normality by the second interview (‘*it’s done with now and move on’* P8, T2). This was facilitated by the following three processes, described in turn.

Process 4. Accepting and normalising the threats of cancer

The active process of accepting and normalising the threats of testicular cancer was important at helping men to get on with life and move forward after the disease, particularly in reconciling the permanent change to their body.

4.1 Accepting and normalising cancer in young adulthood

Acceptance of having cancer in young adulthood seemed to facilitate the transition from the shock of the diagnosis and treatment phase to a state of normality afterwards.

> *'cos it's part of my life, it's happened, I can't change it, so you might as well use it productively rather than try and ignore any existence of it'* (P13, T1, 27 yrs, In a Relationship, Surgery)

Perceiving the timing of the disease as better in comparison to previous or future stages in their lives helped them accept when the disease had struck. Some even perceived the timing as a positive advantage, in terms of giving them time to implement changes to their lives or in bringing the future forward. Some could also have difficulty accepting the timing of cancer in young adulthood, despite deriving positive outcomes.

For several men, the discrepancy between their expectations and their actual experience of testicular cancer meant that some felt a strong sense of ambivalence over whether they had accepted the disease. Ambivalent acceptance was often due to the brevity of the experience, the discrepancies between their experiences and societal views of cancer and ambiguity over the perceived threat of recurrence.

> '*I don't know whether I've fully accepted it, even though I'm completely treatment free and I've gone through it and I've beaten it, as it were, I suppose I'm still waiting for it to really sink in, that I had that and now it's gone, and that I ever had it at all..'* (P2, T1, 24 yrs, Single, Surgery)

Whilst participants commonly felt that the rapid treatment pathway was beneficial at helping them avoid dwelling on the threats in the short-term, they also felt it compounded their ambivalence over their experience. Men's ambivalence was also attributed to the lack of symptoms or feeling ill, particularly if participants did not have to receive treatment after orchidectomy. One participant (P23, T1) who had one dose of chemotherapy felt that having some treatment made it '*feel a bit more like real cancer'*.

> *'it's really bizarre to have had something which in some ways is I suppose life limiting… and yet not to have felt any pain or symptoms with it, and to be given the all clear, I don't really say I have fought cancer…It's this surreal thing of has this really happened, that's the overriding sense at the moment'* (P19, T1, 39 yrs, Married, Surgery)

By Time 2 interviews, most participants had resolved these feelings, apart from P10 (see negative case example) as well as P2 who was diagnosed with a recurrence.

A minority of men discussed periods of feeling *'low'* and stress from time-to-time following returning to work, yet sought to find a sense of balance in their lives through normalising and accepting their feelings and disclosing their concerns to others.

> *'some days you feel absolutely fine and silly little things remind you that you actually had cancer…. for a while I felt low and yeah I admit to my wife I'd thought at some stages I was maybe suffering from depression….I felt not lonely, sort of very pressurised and everything I done, was very snappy, and then all of a sudden out the blue you have a good week, two weeks and things are fine, but things easily build, got on top of me very quickly, so I'd come back down again, no I never went to the doctors or anything, from time to time I still do get these times, but I'm assume that's life of living with cancer, and a young family and pressures of life'* (P1, T2, 36 yrs, Married, Surgery+R*)

4.2 Accepting a new body normality and appearance changes

The process of active acceptance towards a new body normality enabled men to get on with their lives. Men were generally unconcerned about having only one testicle, which was often discussed as a relatively insignificant loss. The loss of a testicle was compared to the threat to mortality, which reduced the salience of body image concerns. Men perceived similarities in terms of the function, aesthetics and their feelings towards the new 'normal' body (*'I don't feel any different now'* P7, T2). In men who had surgery alone, knowing their fertility was likely to be unaffected also reinforced this view.

> *'[I] don't feel there's anything making you different, it's certainly not that it's leaving you with a limp which is a permanent reminder, you're not scarred on the outside or anything like that, it doesn't bother you it doesn't affect how you move on if you want a family it doesn't affect any of that, so fine…. At the end of the day I'd rather have one and be here!'* (P12, T2, 37 yrs, Married, Surgery)

The removal of the testicle as the site of the cancer was even perceived as a psychological advantage.

> *'you think what used to be in there is now not in there anymore so that subconsciously makes you feel a bit healthier'* (P12, T1, 37 yrs, In a relationship, Surgery)

It was evident that the transition from an initial state of fearfulness before the orchidectomy, to accepting and normalising the loss was often a quick process. Some men recalled difficulties initially adjusting to the loss, yet these concerns appeared highly transient, often lasting for only a few days or weeks. Whilst men felt that their new body normality did not currently affect general self-confidence or feelings of masculinity; some admitted this had been initially threatened, but had improved over time as they tested out their capabilities and feelings.

> '*I'm that sort of person that I had a bit of a low but picked myself up and carried on, I can do everything exactly the same as any other*

> *person, intercourse, sport, everything so it's not really anything that. Yeah it's just your personal self-esteem, but obviously some people can take it the other way and go down to a sort of low, but I was the opposite and a couple of weeks and I just sort of got on with it'* (P1, T1, 36 yrs, Married, Surgery+R*)

Men challenged cultural assumptions around the body and asserted that the presence of both testicles was not felt to be an important or valued part of being male. Participants emphasised other aspects of masculinity, such as involvement in sports or fitness, being a father and husband or having a career, perceived to be more highly valued, and so de-valued the loss.

> *'It doesn't make me any less of a bloke than the bloke next door; it doesn't really change me at all'* (P16, T1, 38 yrs, Married, Surgery+C)

Some single men questioned whether this sense of positive adjustment to their body image would diminish over time. Yet these doubts were unfounded at Time 2 interviews, as stability in men's feelings towards their body was evident over time. In fact, some tested out their feelings towards their body, which confirmed their lack of self-consciousness.

> *'I'm one of those people that it just doesn't matter to me, I am who I am and I can change what I can change and I can't change what I can't and perhaps it's gonna be, it's gonna hit me in a few months that I'm gonna have to get a prosthetic cos I really feel like I'm not who I was before and I could absolutely understand that but right*

> *now it's just not a priority for me, it hasn't really changed how I feel'* (P2, T1, 24 yrs, Single, Surgery+C*)

Some single participants even reframed the change to their body in a positive way, in terms of heightening a sense of unique identity. Others also seemed to have incorporated the loss of their testicle into their identity, as it symbolised their status and pride in having been through cancer (*'it's who I am now'* P5, T2).

> *'I thought I'd be a little bit more self-conscious about it there, but I'm still me, aren't it, at the end of the day it doesn't make no difference, it's just I've got a few battle wounds to talk about now instead of nothing… I'm not worried about like everything downstairs, it's fine, I've got one [testicle] now instead of two basically, that's it.'* (P20, T1, 22 yrs, Single, Surgery+C**)

Some single men questioned whether there would be barriers to meeting future partners, but quickly appeared to relinquish these concerns, as they felt generally as confident as they did before testicular cancer ('*I don't think it's gonna be a problem, certainly not with my confidence'* P2, T1). Another single participant (P18) reported having an initial need to compensate for the loss of a testicle through needing to prove his own physical ability, fitness and strength.

> *'initially I just wanted to get back to where I was before, and probably a little bit not to prove it to anybody else but to myself, cos I think from a bloke's point of view cos you've lost one of your bits and pieces, you feel that you kind of you still wanna be like a blokey*

> *kind of.. if that makes sense, and not to prove to anybody else cos I'm not competitive with anybody else, but with myself I'm always try and do me best'* (P18, T2, 44 yrs, Single, Surgery+C)

On the whole, those who had already achieved key milestones of young adulthood, namely fatherhood and marriage, felt that they didn't have anything to prove, as they found a sense of security in already having completed the 'expected' milestones of masculinity.

> *'you don't necessarily feel you have anything to prove, you've done a certain amount of what is naturally expected of you, there is an expectation that at some stage you will get into a relationship, you'll have family, x,y,z, I've already gone down that road, and emotionally they can go and give an awful lot of emotional support'* (P9, T2, 44 yrs, Married, Surgery+C)

Being in a committed relationship was perceived as important at increasing men's sense of security through their partners' acceptance of their body. This seemed to temper the threat to body image and masculinity. These men felt the loss of a testicle was not a visible difference to anyone other than their spouse. Therefore, partnered men appeared to more easily dismantle the threats of the disease, particularly to this area.

> *'I think a bit part of that is simply my wife's attitude to me and the fact that she's interested in all of me… not just 'oh your no good as a naked male model now so forget it' and having that sense of security of relationship… means I don't have to get hung up about it and that does mean I can be more brazen about it... So I'm not a*

> *porn star, I don't do naked modelling, I don't want to father any more children, I don't prance around naked when I'm getting changed in swimming pools'* (P19, T1, 39 yrs, Married, Surgery)

For these reasons, all but two participants decided against opting for a prosthetic testicle. Other reasons included not wanting an '*imposter'* (P18, T1) in the body after the cancer was removed and concerns over how the prosthesis would feel. Out of the men who opted for a prosthetic testicle, one participant (P13, T1) stated this was due to concerns over what his partner would think. Another participant (P25, T1) gave being single and wanting to avoid immediate disclosure of his cancer survivor status to potential romantic partners as the reason. A prosthetic testicle helped him regain a sense of control over the threat to future relationships.

> *'I decided to go for it [prosthetic], mainly because I'm single, so I'd have to have that conversation at some point, but when it first comes up it's probably not the time I want to be having that conversation, so I could save it for when I was ready to have it'* (P25, T1, 30 yrs, Single, Surgery+C)

After having the prosthesis put in immediately after the orchidectomy, these participants maintained they had no body image issues, and were satisfied with the procedure.

Some participants felt unconcerned over visible changes to appearance, such as alopecia in particular, which was deemed socially acceptable, and sometimes used humour as a way of dealing with social tensions.

> ‘*Obviously when all my hair fell out, the lads thought it was hilarious, there’s no point getting upset about it’* (P16, T1, 38 yrs, Married, Surgery+C)

Yet some men who received treatment found changes in visible appearance more threatening than the loss of a testicle, as some were unexpectedly concerned, particularly over weight gain or alopecia (‘*miss my hair*’ P25, T1). Some felt these visible signs of difference impacted on their identity through affecting how others reacted to them, which could threaten confidence in social situations (‘*you kind of lose a little bit of your identity’* P2, T2). However this was often transient, as during recovery men felt their appearance quickly returned to normal, and in getting on with life the salience of these issues seemed to lessen. Weight gain was an ongoing issue for a few men, although often reframed as a minor issue which was dealt with by making plans to re-establish fitness.

> ‘*you do get a little bit self-conscious, mine wasn’t to do with the operation I had it was more the side effects of the drugs, I think it’s the steroids that make you put on the weight, so yeah you do get a bit self-conscious....after that I think it was just low self-esteem I think and a bit self-conscious of how I looked cos of the skin falling off and the swelling and the spots and putting on the weight, so you do like feel different emotions, I think mine was, I was more angry on one day and then self-conscious and a bit paranoid about how I looked afterwards’* (P5, T1, 28 yrs, Married, Surgery+C)

Some of these men, particularly single and younger men, could struggle to restore feelings of confidence, particularly in social situations.

> ‘*as soon as you have chemo it kind of changes everything so yeah, confidence I think’s been an issue, there’s been certain things I just don’t want to do, don’t always want to be out and about, places where, it’s really easy to hide under a hat’* (P2, T2, 24 yrs, Single, Surgery+C*)

Men sought to guard their children against distress over appearance changes, which was often the focus of men’s concerns.

> ‘*it was just trying to think of ways to tell the kids that I was ill cos they were gonna know cos obviously my hair was gonna fall out, I was more worried about how they were gonna feel I think’* (P5, T1, 28 yrs, Married, Surgery+C)

Process 5. Preserving and enhancing the normal self

In some men, testicular cancer had threatened, albeit temporarily, their sense of masculine identity. Yet most men in this sample seemed to quickly restore their disrupted identity which was achieved by adopting strategies to defend against illness centrality, construct an enhanced sense of personhood and re-establish their work roles. These strategies compartmentalised the illness, and so protected men against adoption of a ‘cancer identity’ or as someone in the ‘sick role’ as opposed to their normal self.

5.1 Defending against illness centrality

During treatment and early recovery, men sought to preserve their normal self and regain aspects of their lives which had been disrupted, such as their *work or achieving self*. Men strove to maintain social activities where possible, trying to maintain their *social or interpersonal self*. This was achieved through defending against the idea of 'illness centrality', whereby the illness was not seen as central to their sense of self. This helped some men maintain hope that life would return to normal after treatment. Most men did not see testicular cancer as a lasting threat to their identity, due to perceptions of the minor significance of the disease as well as having previously reframed the threat of testicular cancer.

> *'I always knew I was going to go back to work, I always knew I was going to get back to my football, get back to the gym, get back to being me, I was always going to, that was never going to change, I was never going to change'* (P20, T1, 22 yrs, Single, Surgery+C**)

Participants distanced themselves from including 'cancer survivor' as part of their identity and instead emphasised other aspects of their lives which were more central to their identity, such as fatherhood or work.

> *'It's just one part of thousands of one of the things that happen in your life.. I don't see it as a defining part of me'* (P9, T1, 44 yrs, Married, Surgery+C)

> '*The security from those relationships hasn't changed, and the relationships with parents and siblings hasn't changed, and so my*

> *identity in many ways I don't feel has changed'* (P19, T1, 39 yrs, Married, Surgery)

5.2 Re-establishing normality through work

Returning to work helped to re-establish a sense of normality following testicular cancer, and signalled the end of their role as a cancer patient. This also contributed to a sense of 'moving on' after cancer and helped to preserve their identity. Work helped to dismantle the future threat of the disease through maintaining a 'normal' identity, particularly with the return of day-to-day interactions with colleagues.

> *'I think going back to work is getting back to normality, it's getting your life back to normal…when you start getting back to work and things being normal you start to pick up again, people treating you normally'* (P5, T1, 28 yrs, Married, Surgery+C)

Amongst those treated by surgery alone or small doses of chemotherapy, some felt only minimal time off work was needed, and made comparisons to more minor scenarios.

> *'I spent less time off work than if I'd had a bad back!'* (P9, T2, 44 yrs, Married, Surgery+C)

By Time 2, some men had made changes to their working lives, such as working fewer hours than before, which was often influenced by perceiving family time as more of a priority over earning money ('*you sit and think I shouldn't be working quite so hard cos there's more to life'* P8, T2). This resulted in a renegotiation of identity as men became less work-orientated, and more family-orientated, and seemed to be confident in breaking out of ‘traditional’ gender roles they had held before cancer. Therefore, normality in their working and home lives was sometimes felt to be enhanced after testicular cancer.

> ‘*I try and certainly be more at home and when I’m at home I try to do more to help out or just to play with the little un or whatever cos it could have been so much worse really…I try not to take things for granted’* (P16, T2, 38 yrs, Married, Surgery+C)

In one case (P14), the participant had lowered drive and desire to work after a recurrence of testicular cancer, as it led him to question and reassess the meaning of work in the face of mortality, which had ceased by Time 2.

> *‘You have that reflection, well why am I coming to work? What’s all this for? What’s it all about? and then you kind of think about your dreams and aspirations and you think I want to be thinking about those…..so there’s a feeling of redundancy coupled with what’s the point*’ (P14, T1, 31 yrs, Married, Surgery+C*****)

The experience had prompted some men to change their careers. However, this desire for career change could be disrupted by a medical history of having cancer, and younger men in the sample felt the disease could stall work plans, potentially disrupting their future careers, at least temporarily.

> *‘Just the only real issue for me is [work]…it’s just having that word [cancer] in your life, slows things down’* (P17, T2, 27 yrs, Single, Surgery+C)

> *‘I think it’s inhibited a lot of.. I had a decent job I was going places when I got diagnosed the first time that meant I had to stop that job,*

> *and then I got another job after I got better which I had to just quit, so yeah I think it's really inhibited probably my career, yeah it's changed a lot… I think it's changed a massive amount'* (P2, T2, 24 yrs, Single, Surgery+C*)

Due to the effects of treatment, some men took the option of a gradual return to full-time hours. Some had suffered financially, so felt under pressure to return to full-time work or even work extra hours. Particularly for men on lower incomes, the post treatment period could mean a struggle to regain financial losses in order to support the family, which was an added burden. Some men reframed their financial worries as being a distraction from fears about their cancer.

> *'I spent more time on my financial affairs and trying to get that sorted out, but I suppose again you could look at it and say well that took my mind off the actual medical side of things, I basically was in a bit of financial straits for a while really'* (P18, T2, 44 yrs, Single, Surgery+C+R)

By Time 2, some men reported struggling initially as they attempted to balance their need to recoup financial losses with tiredness levels and family time.

> *'I think financially it has an impact, you don't realise how much it costs to get to [hospital] and back and paying for the parking and missing out on hours at work that I could have done, I think we're in about a thousand pound worse off since I had chemotherapy which*

> *is quite a bit of money when you're trying to support your family'* (P5, T2, 28 yrs, Married, Surgery+C)

In some cases, men's determination to push themselves back into work was also influenced by the desire to prove their ability at coping and in being a provider for the family. Self-employment also added extra pressure on men to return to work quickly. In fact, struggling with returning to work could result in stress and occasional depressive moods in some. Over time, realising their need for self-care due to greater fatigue, men made adjustments and some were able to find a sense of balance in their lives again and felt better able to manage work-related stress. This ability to find a better balance was influenced by drawing upon their changed priorities in life, namely prioritising close relationships.

> '*yeah probably going back to work too early, so the stresses from that, and then obviously the stresses from going through radiotherapy, so I'd say probably a month to 6 weeks after that I started getting this sort of dips of what I'd call lows, but like I say there's slowly sort of disappearing yeah I still get them from time to time, but not for as long, you just sort of learn to deal with them and just get on with it'* (P1, T2, 36 yrs, Married, Surgery+R*)

For P1, making the most of life in the form of spending more time with his family, normalising and accepting his *'low'* feelings, disclosing his feelings to his spouse and with peers helped him to get through this difficult period after treatment completion.

5.3 Striving to regain physical health normality

For some men, returning to normality meant adjusting to a ‘new normal’ after treatment, particularly with regards to temporary changes to their physical health. Men sought to regain their physical health and vitality, particularly those who had received treatment. Some admitted struggling with confidence related to the loss of fitness and strength, particularly if they had received longer treatment or had a recurrence, so they sought to re-establish their exercise regimes. One participant (P14) described how treatment for a recurrence had threatened his sense of being youthful as he felt he had lost his sporting prowess and that treatment had pushed him over the threshold from youth to middle age, doubting whether he could recover his ‘pre cancer’ fitness.

> *‘In terms of how I perceive myself, yeah I feel as if certainly the changes that I went through…it feels as if it’s almost a threshold between youth and dare I say it middle/old age, that’s a definite feeling of right I currently play [sport] with a group of guys….whereas now I’m at a point where it’s like maybe I should just give it up, I’m not gonna be able to recover enough to be as fit as them…yeah I think that feeling of.. I won’t able to go back and be youthful again because it feels as if almost as if my body has aged quite a lot over a 3 or 4 month period, it’s been through a lot..’* (P14, T1, 31 yrs, Married, Surgery+C*)

Participants could sometimes encounter issues with tiredness or fatigue once treatment was over, although this was often not described as a major difficulty. Whilst some men returned to normality quicker than they expected, a few who had longer treatment were surprised at the duration of fatigue and of not going back to pre-cancer energy levels when they expected. Adjustment involved altering their expectations over the timing of their recovery, and reframing the threat more positively.

> *'you look forward to coming back, to getting back into the saddle and doing things, getting into it, so it was quite a shock to the system realising cos I thought I would get back to almost as you left off..'*
>
> *Interviewer: 'how do you find that?'*
>
> *'Not really good, a bit disappointing, so I'm quite positive and you've got to be realistic, so there's always two ways of looking at things, glass half full* (P18, T1, 44 yrs, Single, Surgery+C)

One participant (P10) described ongoing fatigue and concentration problems despite being treated by surgery alone, expressing frustration over the lack of explanation for this.

> '*I'm constantly tired all the time….and I can't remember anything, absolutely ridiculous, and I mean I used to I can't remember anything, I can't even remember what I did yesterday, I have a constant to do list, with just to remind myself, I'm getting myself more confused than having lists written down, but yeah I do get tired ever so quick, and I can wake up in the morning and I'm tired, absolutely shattered'* (P10, T1, 41 yrs, Married, Surgery)

Some of these men questioned whether hormonal influences such as lower testosterone levels were a causal factor, and wanted better information from clinicians on whether this was the case. These men were offered a blood test to screen for testosterone levels, but were unclear of the meaning of the results which were often not explained. Feeling left in the dark by their consultant seemed to contribute to confusion over the cause of tiredness, and whether these changes would be transient or enduring (‘*does your body adjust to it?’* P9, T1).

> *‘[Health Professionals] didn’t address things like.. if I’m having a testicle removed, that testicle has a function, what happens to that functionality? How does your body deal with that? Do I need things like testosterone replacement? That wasn’t anything that was ever mentioned until I asked about it’* (P9, T1, 44 yrs, Married, Surgery+C)

Other men questioned whether the cause of fatigue was due to long periods of inactivity, ‘*being lazy’* (P7), or having young children. Some men chose to accept and normalise fatigue as part of living with cancer and returning to the pressures of family life and a busy lifestyle.

> *‘tiredness is the only thing that has sort of got to me, whether it is testosterone levels or anything like that I don’t know…. it doesn’t help I’m working the unsocial hours I work, like split shifts and nights, and obviously a young family as well’* (P1, T1, 36 yrs, Married, Surgery+R*)

Therefore, some men wanted advice on the ‘normal’ recovery trajectory and duration of fatigue and how to manage it better, yet were sometimes reluctant to raise these issues with their clinician. Knowing ‘what to expect’ seemed important for men to feel in control and so refocus on striving towards normality.

5.4 Constructing an enhanced sense of personhood

Some men felt that their masculine identity was unaffected by testicular cancer, particularly if they had already achieved the ‘expected’ milestones of masculinity. In a minority of men, especially those who had not achieved these milestones, they engaged in strategies to enhance their sense of personhood. Whilst the disease seemed to threaten masculine sexuality in some of these men, this was not often disrupted for long, due to these strategies of self-enhancement. Firstly, some men seemed to suggest that having the disease had enhanced their self-identity through the sense of pride and achievement in knowing they had ‘coped well’ and in being able to maintain control over their emotions.

> ‘*Gives me more of a sense of like pride almost, like I should be proud of the fact that I’ve beat this*’ (P20, T1, 22 yrs, Single, Surgery+C**)

This sense of pride and increased self-knowledge meant that some men felt more unique and authentic, through being less concerned with other’s opinions of them and of being part of the crowd (‘*comfortable in your own skin*’ P20, T1). Being able to retain their role in supporting the family, both financially and emotionally also reinforced men's feelings of achievement and masculine identity.

> *'I don't think anyone's psychologically prepared for any news like this, it really did kind of defines who you are as a person once you find out something like this and you learn a lot about yourself and how you chose to take it and how you chose to deal with it I suppose…Certainly with my friends and stuff like that it's been another thing to make me a little bit more unique I suppose'* (P2, T1, 24 yrs, Single, Surgery)

Men also discussed a sense of self-improvement after having overcome adversity when dealing with cancer.

> *'I think it's improved me as a person to be honest with you, me outlook on it, I was never negative before, but now I just most things are water off a ducks back now, it just puts things into perspective'* (P18, T2, 44 yrs, Single, Surgery+C+R)

For the proportion of men who had not achieved all of the important milestones of masculinity, they emphasised the importance of having an enhanced sense of personhood as overriding any concerns over the negative effects of the illness, such as losing a testicle.

> *'It actually makes you more of person, I said person instead of man there, but yeah I think it makes you more of a person and so you've grown as an individual and I don't think from that side of it physically or going through it or anything else it's not really, and I*

> *think you yeah you feel better for coming through it obviously, rather than be concerned that you've only got one ball [laughs]'* (P14, T2, 31 yrs, Married, Surgery+C*)

As all men had derived some positive outcomes from the experience, this also contributed to the sense of an enhanced personhood. Participants seemed to minimise the role of cancer in prompting these changes, and maximise their own role in shaping and controlling their post cancer lives.

> '*It sounds stupid but it's quite a positive experience, well I made it into a positive experience, with how you deal with it'* (P5, T2, 28 yrs, Married, Surgery+C)

Some men took pride in their willingness and openness in telling peers about the signs and symptoms of testicular cancer. This seemed to promote masculinity and status as they gained confidence in becoming an 'expert' on testicular cancer awareness, with some alluding to a moral responsibility to tell others. While some men rejected common societal notions of cancer survivorship, such as expectations regarding personal growth or involvement in charity or support groups, others became more involved with cancer charities, possibly reflective of their greater desire for solidarity and connections with cancer peers.

> '*People have phoned me and said have you had some great big life epiphany and leave what you're doing and go and.. no not really [laughs]... life goes on…I haven't had a great big moment, I'm not going to devote my life to charity to be honest or anything like that..'* (P8, T1, 33 yrs, Married, Surgery+C)

Involvement in testicular cancer charities also seemed to increase men’s feelings of enhanced personhood through being able to help others. This desire to give rather than be a recipient of support, as previously discussed, appeared important in helping men preserve and enhance the self, particularly regarding self-confidence.

> *‘It’s given me more confidence knowing that you can pretty much say anything to anyone really’* (P13, T2, 27 yrs, In a Relationship, Surgery)

If men’s sense of masculinity was challenged, the process of constructing an enhanced personhood seemed important in restoring their sense of initial vulnerability. This was particularly the case for single or childless men.

> *‘the word I was going to use was sort of a feeling of vulnerability, in that something’s come along, completely sort of ripped all your image apart as it were, and you cope with that and you learn to be comfortable with that*’ (P14, T1, 31 yrs, Married, Surgery+C*)

Whilst the topic of sexuality or sexual function was not often raised by participants, when it was, this was always mentioned in the context of asserting that their sexual abilities were unaffected. One single participant initially perceived a threat to his masculine sexuality, yet this was tempered by reassurance from the CNS.

> ‘*I think my other worries were, yeah libido, testosterone levels things like that, you know was I gonna be the same person in that way than I was before? That was a big worry, but I mean everything*

> *seemed pretty normal to me, and I was always told that it wasn't the end of the world even if you did, that there was some things that could be done to make sure that that sort of equilibrium was re-balanced, but they were the two big worries but they didn't last long because I was always sort of brought back to earth with its not the end of the world we can do something about it'* (P2, T1, 24 yrs, Single, Surgery+C)

Poorer adjustment in this area arose from the struggle to enhance self-identity which could result in perceptions of an *inadequate self* (see negative case example).

Process 6. Re-establishing a sense of security and relinquishing fears

In order to restore a sense of normality to their psychological wellbeing, participants described learning to let go of the psychological threats of cancer, particularly fears towards the future or a cancer recurrence, enabling them to re-establish a sense of security.

6.1 Holding onto anchors of security

The main psychological challenges for men seemed to be most acute during the diagnosis and treatment phase ('*the worst weeks of my life'* P25, T1). Men felt relieved at treatment completion, valuing a return of independence and being able to *'get on with life'*. They were often determined that they did not need a *'hand to hold'*, referring to masculine 'values' of autonomy and self-reliance.

> *'it was kind of good to have sort of that independence and that… especially when you're a guy and I suppose that dignity aspect, that I didn't have to stay in hospital and have nurses poking around constantly, especially when you're feeling a bit irritable and a bit sort of... I dunno vulnerable as well after an operation like that'* (P2, T1, 24 yrs, single, Surgery).

When returning for regular follow-up appointments, some men felt largely unconcerned, while others struggled with short-term anxiety around this time. Knowing they were 'all clear' signalled feelings of security from the threat of cancer and provided reassurance, even if they denied feeling worried before the consultation. Receiving positive news helped men feel secure about their health and achieve psychological normality, whereby they felt generally unconcerned about cancer on a day-to-day basis. Participants also held onto other anchors of security, such as their relationships, fatherhood status or careers.

> '*I don't worry about going but when I come out it's like yeah result! Like everything's all right, let's press on for the next 3 months, I'm not worried about going, cos if anything was wrong, you're going to the right place'* (P12, T2, 37 yrs, Married, Surgery)

Attending follow-up appointments could disrupt men's sense that life had returned to normality, as going into the hospital was a poignant reminder of their experience, and some disliked having to disrupt work in order to attend.

> *'I feel like it's too much [contact with health professionals] if anything now I feel like I don't need it, in the nicest possible way like leave me alone I'll come back when I need to.. I feel like it's a bit of wasted time just going back when there is nothing wrong, I mean I know with cancer it can come back and you won't know… I guess I'm stubborn'* (P17, T2, 27 yrs, Single, Surgery+C)

Face-to-face follow-up appointments were sometimes deemed unnecessary or '*pointless*' if the sole content was to give the 'all clear' without any additional advice or information. Some felt this could be delivered remotely, such as over the telephone. Particularly by Time 2 interview, some participants felt they were getting on with life and were not concerned about cancer or felt any more vulnerable, although discussed the importance of self-checking their remaining testicle.

> '*I don't feel more vulnerable, I don't feel I've got to live for now cos there might not be a tomorrow [laughs] I am just still me, and I'm sure if you ask [wife]..she'll say he's still the same'* (P15, T2, 40 yrs, Married, Surgery)

Men displayed divergent views towards being on a follow-up program for 5 years, with some perceiving being monitored as an *'insurance'* (P5) plan, perceiving themselves to be at an advantage over the normal population, whilst others felt it was excessive and felt competent in telling health professionals if they detected anything wrong ('*I'm a big boy I can tell them if I'm not feeling well'* P8, T1).

> *'it's nice they give you, like a 5 year plan, it does seem a bit extreme in your head, it's come back all clear for 6, 9 months, surely it ain't gonna come back but it's a horrible little aggressive thing that does ruin a lot of people's lives, so it's good that it gives you a long plan, it's comforting cos you think if anything else goes wrong between now and then, if they missed a bit or even a little bit escaped the chemo or whatever you feel like your covered for 5 years, you got 5 years insurance free or whatever, so it's good, the 5 year plan'* (P5, T2, 28 yrs, Married, Surgery+C)

Follow up appointments could therefore provide a source of security for some men, while others found them disruptive to their desire for normality. One participant in particular (see negative case example below) struggled to hold onto the anchors of security and instead, seemed to hold onto the life threatening nature of cancer, which meant he lost a sense of security in his future over time.

6.2 Letting go of fears of recurrence

During early survivorship, relinquishing or letting go of negative thoughts and fears towards a cancer recurrence appeared helpful psychologically and enabled them to get on with life. This involved guarding against rumination and actively choosing not to '*dwell on it'* (P18, T2), which helped prevent the spread of negative thoughts and feelings. Men also attempted to relinquish negative thoughts through focusing on positives.

> *'I think to be honest with you, so easy it can take up your mind….cancer is obviously a medical condition, but it can also mess*

> *up your mind if you let it into your mind and worry about it……what I've found if you allow it to sort of spread if you have a thought come into your head, nip it in the bud and then think how lucky you are and then move onto something else more positive, and treat yourself every day, make the most of every day…it eats away if you're not careful'* (P18, T2, 44 yrs, Single, Surgery+C+R)

Compartmentalising or boxing away the experience was also employed as a way of letting go of the threat of cancer to the future, perceiving it as '*outside of my control*' (P23, T1). Although some discussed occasional thoughts about a recurrence, men generally displayed a pragmatic attitude towards this threat ('*if it happens, it happens*, P15, T1) which often seemed stable over Time 1 and 2 interviews, illustrating that they felt able to tolerate a slightly more uncertain future. Men's self-efficacy at self-checking and willingness to seek help for medical problems if they detected anything was felt to be greater, which also helped them to relinquish this threat.

> '*I know that there is still a risk out there but it doesn't worry me, if it returns then we'll deal with that when it happens and I'll go through the same process, and I won't be as backwards at stepping up I will say I need to go I need to see someone straight away if I have a concern'* (P15, T2, 40 yrs, Married, Surgery)

By Time 2 interviews, a lessening in men's fears was evident with the passing of time, such as with P7, for example.

> *'It's something now I don't even think about…it's done and dusted'* (P7, T2, 43 yrs, In a Relationship, Surgery+C)

Men commonly referred to a '*mind over matter'* (P2) approach as well as holding steadfast beliefs in their ability to overcome the disease, which helped dismantle the threat of disease in one participant treated for advanced testicular cancer (P20). Again holding onto positive illness perceptions helped dismantle the threat of mortality.

> '*It did affect me, but I didn't, I never once seen it as like a problem.. I never thought oh, this is something that's not achievable, this is something that's not going to go away…I always seen it as something I was always going to beat, so I never really looked at it in the other sense…that's probably the best thing really, just having a positive mental attitude, rather than being miserable'* (P20, T1, 22 yrs, Single, Surgery+C**)
>
> *'I suppose interestingly death wasn't really something I thought about, I was always so sure that, quite determined that this wasn't gonna be the thing that was gonna sort of, yeah kill me, it was just a hiccup, and I don't know whether that was a bit of naivety and perhaps a little bit of denial but, I dunno.. death was never really a worry which I thought it would be a big worry'* (P2, T1, 24 yrs, Single, Surgery)

By Time 2, some men admitted having occasional set-backs, as the aforementioned strategies were not always successful, and feelings of self-pity could arise. Some admitted they had occasional fears of the cancer coming back in the future, although these fears were not felt to be severe or enduring in many cases ('*it's not an ever present feeling'* P13, T2).

> *'I wouldn't say setbacks but you have days or moments where you do feel a bit sorry for yourself, but it's kind of just get on with it, I think that's the key to it'* (P18, T2, 44 yrs, Single, Surgery+C+R)

In one participant (P17) at Time 2, whilst stating he was generally unconcerned over a recurrence on a day-to-day basis, once the tape ended he admitted occasional *'frightened feelings'* over whether carrying on smoking would lead to lung cancer. A sense of fatalism over his future health appeared to be a way of defending against these fears, although this did not translate to stopping smoking.

> *'if I started feeling different or tighter in the lungs I would just stop [smoking] straight up there and then, but it's like I say, ... it's like I think well I don't wanna say undefeatable, cos that's too much… but almost, it's like nothing really bothers me cos if it something's gonna happen it will happen, either way, sort of cross every bridge as you get there'* (P17, T2, 27 yrs, Single, Surgery+C)

As participants often adjusted quickly and positively to the disease, getting news of a recurrence was an unexpected major '*body blow'* (P1) and disappointment. Men had to make sense of living with the impact of more detrimental consequences of treatment, which could evoke greater uncertainty over the future, including a greater threat to fertility. Knowing that young adult life was on hold for a second time was difficult to accept.

> '*I've got so much to try and do and achieve, and things are getting sorted or moving the right direction and then cut… and you just*

> *have to stop and yeah that was hard to…. massively hard to take*' (P14, T1, 31 yrs, Married, Surgery+C*)

A recurrence also heightened perceptions of the seriousness of testicular cancer, which men had sometimes not felt during the initial diagnosis ('*it's that realisation of yeah, it's you'* P1, T2). In all three of these men, their initial treatment had been surgery alone.

> *'I had my operation the first time it was kind of like the difficulty to get your head round that it couldn't grow back there again or anything, you got rid of quite a significant thing, and then for it to start again in a different place is kind of like.. those games where you got to hit a mole on the head with a hammer no matter where you go they just pop up in a different place, that can be a bit scary, so second time round just thinking s**t it's the second time…I suppose that's always a worry and that's something difficult that you don't always see the first time'* (P2, T2, 24 yrs, Single, Surgery+C*)

Men derived more positive outcomes from the initial diagnosis of testicular cancer, compared to the recurrence, as this led to more negative consequences of treatment.

> '*We had the life changing moment we were going towards that, and then it was just right you've just got to stop what you're doing, oh not again, so the first experience was a positive one, the second experience was just a pain in the arse really'* (P14, T1, 31 yrs, Married, Surgery+C*)

P2 was the only participant to have a recurrence between Time 1 and 2 interviews, and was facing the possibility of having to undergo more surgery at Time 2. While he drew many positives from the initial diagnosis, he found it difficult to hold onto these positive gains at Time 2, and so struggled with dismantling fears towards a potentially disrupted future ('*at the moment, it's kind of difficult to see many positives'* P2, T2). Following the recurrence, one participant (P14) felt generally more risk averse, which was attributed to having a greater realisation of his own mortality and vulnerability. Therefore, a recurrence could heighten men's sense of vulnerability, so they had to strive harder to restore a sense of normality in their lives.

> '*before [cancer] I'd sort of fly into things and get involved and always feel that I could do them and achieve them whereas now I'm thinking more about it, I don't know whether it's a maturity, but I'm thinking should we do that, well this could happen, and that's very unlike me, the me of the old, so there's definitely been a change.. I could put it down to just maturity but it seems to be a distinct change from now and maybe 12 months ago, so that's hard....it's almost like a thank God I'm here, lucky to be alive type mentality, and so you don't wanna risk that, and that, yeah you've done a lot of thinking over, well for me a 6 month period, and it's like you don't want to test that fallibility again so you just sort of exist'* (P14, T2, 31 yrs, Married, Surgery+C*)

6.3 Accepting a more precarious life and living more ‘in the now’

The diagnosis could challenge men’s assumptions of invincibility, so men sought to find a middle ground between their fears of mortality and a heightened awareness of vulnerability, and accept the precarious nature of life.

> ‘*R: and how do you feel about the future?*
>
> *‘more positive than I did quite a few months ago, yeah you can see that there is one now after having come through it all, you still get apprehensive when you go for these appointments but I don’t dwell on them, yeah I just know that I’ve been very lucky, and I’m glad that I’m able to have a future, the future is a lot brighter than it could have been’* (P16, T2, 38 yrs, Married, Surgery+C)

Realising and accepting the precarious nature of life following their diagnosis could lead to a greater sense of living more ‘in the now’. Feeling less inhibited by fear men discussed the need to ‘*carpe diem’* or ‘seize the day’ (P25, T1) which helped participants to get on with life. This was important at helping men to dismantle the perceived threat of imminent mortality, as living life more ‘in the present moment’ seemed to reduce the salience of this threat and dismantle the threat to the future as it helped men refocus their lives.

> *‘You never know when something else will happen and you could be worrying about a cancer that you may or may not have in 5 years when you get hit by a bus…it just heightens that sense of we’re not*

> *here forever. So I think it's helped give us that sense of actually this needs to happen, let's make it happen.. so I think it gives us just a bit more sense of urgency'* (P19, T1, 39 yrs, Married, Surgery)

As a consequence of having testicular cancer at a young age, the future was seen as brought forward as the disease prompted participants to make changes earlier than originally intended.

> *'my future's probably been brought closer to what I have always wanted rather than you know, rather than just to leave it out there as a dream and aspiration… so in that respect it's been a positive experience massively'* (P14, T1, 31 yrs, Married, Surgery+C*)

This attitude of 'getting on with it' and refusal to live in fear of the next appointment helped men to quickly move on and refocus their lives after cancer (*'I'm not gonna live in fear of the next appointment I've just gotta get on with it'* P19, T1).

6.4 Accepting the need to 'wait and see' over fertility

In those who had received adjuvant treatment after orchidectomy, men were aware that the treatment could threaten their future chances of fatherhood. For those who wanted to start a family or have more children in the imminent future, the threat to future fatherhood was often the most concerning issue during early recovery, which magnified the significance and biographical disruption of the disease. Many adopted the attitude of pragmatic acceptance towards this threat, yet feared a negative result and what may await them and their spouse should IVF be required. Men could struggle if they dwelt on these fears, rather than accepting that this was something they could not change.

> '*besides that [fertility issues] I'd say everything is pretty much back to normal, which is good, apart from obviously the kid thing which is still on me mind, but it's to me you have to deal with it when you come to it, you can't really do anything about it until you get tested…can and can't you have kids again, that's the only thing that plays on your mind at the moment'* (P5, T2, 28 yrs, Married, Surgery+C)

> '*I'll find out in a couple of months, so I'm not concerned, I'd like it to be natural if the next one was to happen but it's not the end of the world if it's not'* (P16, T2, 38 yrs, Married, Surgeyr+C)

Conversely, men who considered their families to be completed were unconcerned over losing fertility and some even hoped sterility would be guaranteed, so they would not need to use contraception. Yet single men also seemed relatively unconcerned, particularly if they didn't plan on having children in the imminent future, with some expressing confidence in their body's ability to recover from the treatment. These men often dealt with this issue by letting go of their concerns as something to be dealt with in the future. Importantly, men also had a strong sense of security in their future after banking sperm, although the number of years given for free varied, with some men anxious of the financial implications of having to pay for further storage of sperm.

> ‘*not being able to have kids is something that will change your life it’s something that if you decide I can’t afford that £200 and they throw it [sperm] in the bin you never got that opportunity to have kids again’* (P5, T2, 28 yrs, Married, Surgery+C)

One younger, single participant (P20) even reframed the potential loss of fertility as an advantage, a view which seemed to enable him to regain control and defend against the threat to his future. He felt that by potentially losing his fertility, he had more control and power in determining his future, in terms of being able to choose the future mother of his children, in comparison to peers who had been forced into premature fatherhood.

> *‘I’ve got the power to pick who I want my girlfriend to be, and I’ve got the power to pick who I want the mother of my child to be, so I’m one-nil up as far as I’m concerned, I get to pick who it is at the moment, that’s not a bad thing at all, that’s brilliant, because I could have got someone pregnant and had to deal with the consequences’* (P20, T1, 22 yrs, Single, Surgery+C**)

For one participant (P14) who was undergoing IVF treatment with his partner by Time 2, he expressed feelings of resentment and hatred towards the disease which deepened over time, as it put the couple’s hopes of parenthood into jeopardy. These feelings seemed a barrier to him accepting the impact of cancer on fertility.

> *‘Just the resentment, you can’t be as you were… yeah that one’s a bit more of a difficult one to get over, lots of our friends are obviously having babies and going through that thing which is*

> *something that we feel that we're more than prepared to do…it's that sort of that resentment, so you know I know that I'll never be able to look back on the cancer and think oh well that was a bit tough but I'm so glad it happened, there's always going be a bit of hatred, bit of resentment there'* (P14, T2, 31 yrs, Married, Surgey+C*)

Alongside feelings of hatred towards the disease's legacy on aspirations of parenthood, he also felt that overall, life was better for having testicular cancer. This showed his attempts at holding onto the positive outcomes of the disease. Therefore, testicular cancer was seen as simultaneously accelerating and halting the future.

> '*overall, I know that we're in a better place for having gone through the cancer, and life is on the whole extremely good, we're not counting what we don't have, we're always counting what we do have'* (P14, T2, 31 yrs, Married, Surgey+C*)

One single man expressed some concerns over the impact of fertility issues on future relationships, predicting that the disease could cause future disruption.

> *'maybe in a few years' time if I do want to have children, that will be one of the massive effects that it's had, that could probably put a strain on a relationship*' (P2, T2, 24 yrs, Single, Surgery+C*)

Therefore, coming to terms with fertility issues in men who desired children meant an acceptance of the need to 'wait and see' over their fertility status or the outcome of IVF, with single men in particular choosing to reframe it as an advantage. These strategies enabled men to get on with their lives and regain a sense of control over the future.

Summary of Transition 2: striving to get on with life and restore normality

To summarise, the active processes involved in *striving to get on with life and restore normality* helped men to dismantle the threats of the disease, particularly towards the future. This enabled them to regain a sense of control over the threats. Poorer adjustment involved a sense of ambivalent acceptance towards the disease, struggling to relinquish threats to the future and tolerate uncertainty, struggling with feelings of resentment over loss of fertility and struggling to balance work with self-care. In a small minority of participants, these processes seemed to lead to a sense of mild depression and anxiety, although none appeared to exhibit major distress.

Negative case comparison

Holding onto the threats of cancer: the process of negative adjustment

A negative adjustment trajectory was characterised by the process of *holding onto the threats of cancer* (see Figure 3). This involved the opposing transitions of *losing a sense of perspective over the threats of cancer* (Transition 1) and *struggling to get on with life and restore normality* (Transition 2). While areas where participants could struggle have been highlighted throughout this chapter, one participant (P10) was a clear negative case. Comparisons with this case highlight the opposing processes which explain a negative adjustment trajectory over time. These processes appeared more important than treatment or demographic variables as this participant was married, had children and received surgery alone. Comparisons are highlighted between the processes involved in negative (highlighted in red) and positive adjustment. While other men in the sample struggled with specific areas, this case was chosen as he struggled with many areas and appeared psychologically worse at Time 2.

Transition 1: Gaining a sense of perspective (vs. losing a sense of perspective)

This participant appeared to be *losing a sense of perspective* over time, produced by the following processes.

Process 1. Minimising the significance of cancer (vs. appraising as a major event and struggling to gain a sense of coherence)

In contrast to most of the sample who often minimised the significance of testicular cancer, P10's appraisals of the significance of cancer changed from a minor event at Time 1 (*'it's just something else on your CV isn't it'* P10, T1) to a major one at Time 2 ('*it's a major thing'* P10, T2), as the disease was increasingly perceived as more threatening. P10 also struggled to resolve the discrepancies between his prior assumptions about cancer and his actual experience, and was unable to relinquish these prior assumptions he held around cancer being associated with death. This contributed to these negative appraisals and the struggle to gain a sense of coherence over the event. He also struggled to derive a sense of positive meaning from having cancer.

Process 2. Positive reframing of the threats of cancer (vs. holding negative illness perceptions and a generalised view of cancer)

Negative appraisals towards testicular cancer meant that P10 struggled to positively reframe the threats of the disease. In comparison to others, he struggled to make meaningful social or intrapersonal comparisons by Time 2, so was less able to reframe the illness in a less threatening way. By Time 2, he also struggled to hold onto positive illness perceptions which had been more evident at Time 1. Compared to others who perceived the disease as a specific cancer, P10 took a more generalised view of cancer, in perceiving testicular cancer as part of one whole disease. Taking this generalised view seemed to increase feelings of susceptibility to a recurrence in another part of the body.

> '*I don't think that anybody can understand, and heaven forbid I wouldn't wish it on anybody but until you have it, it's a lonely place, cos all you hear of people dying of cancer these days, no one seems to die of anything else'* (P10, T1, 41 yrs, Married, Surgery)

At Time 2, rather than embracing positive discourse surrounding testicular cancer as *'the best cancer to get*', this participant found this discourse undermining. Cancer was also perceived as a more enduring or chronic threat, as opposed to an acute illness. These perceptions were influenced by the struggle to relinquish cultural connotations of cancer.

> *'No matter how good the outcomes are, you still had cancer….because it is such a positive one, that's great, that's great, but you still had it, people go, it's great, and you don't want to seem ungrateful, because you don't want it to be worse, but it's like yeah, but I still had it, it's still there*' (P10, T2, 41 yrs, Married, Surgery)

Process 3. Overcoming the threats through utilising external resources and support (vs. adopting a stoical and silent approach and concealing feelings)

While taking an active approach to seeking support promoted positive adjustment, taking a more stoical and silent approach in terms of concealing feelings led to poorer adjustment in P10. Stoicism was influenced by attempts to protect the feelings of others and a more rigid adherence to 'traditional' masculine values, which led to reluctance in seeking out support. P10 attempted to mask his vulnerability, particularly around male peers, due to fears of others perceiving him in a different way.

> *'I didn't want to tell too many people because of people's reactions… I didn't' want people to go 'leave him alone don't bother him at the moment'. So I just told people I had the flu and I was off for a week, I told a few of my mates and they kind of confirmed my fears, as soon as you mention the word cancer, people move away as if you're going to pass it onto them as if they don't know what to do with you, so I kind of kept it to myself'* (P10, T1, 41 yrs, Married, Surgery)

The ongoing concealment of his feelings from spouses or family members led to a sense of isolation by Time 2, and reluctance in discussing his concerns with health professionals led to confusion over the late effects of treatment and a sense of abandonment as he suffered in silence. These attempts at protecting his masculine identity through concealing feelings and maintaining a positive front (‘*there’s a kind of pressure to say, yeah, you’re fine’* P10, T2) came at the cost of feeling unsupported and isolated, which was a vicious self-perpetuating cycle (‘*it is a lonely place’* P10, T1).

> *‘it has made me feel like that, going [to follow-up consultations], dealt with, come back out, bye, and then you’re in the big wide world to deal with it yourself, and a lot of the time probably the questions you have pop into your head, you think can’t ask that anyway, that’s a little bit stupid to ask that, ‘I told you that, I told you, you’re fine, we’ve given you statistics, what more do you want’, yeah, but I just want a bit more reassurance, I know you told me I’m 92% OK now, the little 8%’s bothering me’* (P10, T2, 41 yrs, Married, Surgery)

This coping style of stoicism and emotional concealment persisted in this participant, in contrast to other participants who seemed to have adopted a more active approach to emotional support seeking by Time 2.

Transition 2: Striving to get on with life and restore normality (vs. struggling to get on with life and restore normality)

In this participant, poorer adjustment was characterised by a *struggle to get on with life and restore normality.*

Process 4. Accepting and normalising the threats of cancer (vs. having a sense of ambivalent acceptance towards having cancer)

This participant in particular had difficulty accepting the timing of cancer in young adulthood, despite being one of the older participants in the sample.

> *it's nice to be able to say you're on the other side and you've come through it, and that's really good to be able to say that, but there's obviously a negative stigma attached to any cancer, no matter how good it is, I had cancer, really? And I think having it, I mean I still class myself as young, although I know I'm old to have this one, it's like really?... that age?* (P10, T2, 41 years, Married, Surgery)

This sense of ambivalent acceptance escalated over time in P10 compared to others who had often resolved these feelings by Time 2, as he had difficulty assimilating the illness into his life narrative.

Process 5. Preserving and enhancing the normal self (vs. struggling to defend against the threat to identity)

In comparison to others, P10 struggled to preserve and enhance a normal self, which explained his feelings of inadequacy and sense of disrupted identity, which plagued him at Time 2. This sense of threatened masculine identity was evident in his role at home as well as around male peers, which was a change he noticed since having testicular cancer.

> *'I don't at times feel good about myself, and then that worries me that I'm perhaps not as good as I should be for my wife and my child*

> *and everything else, and it does bother me, but there doesn't seem an avenue you can go.. to sort it'* (P10, T2, 41 yrs, Married, Surgery)

This struggle to derive positive growth or meaning from the experience or live up to his ideals of survivorship in initiating changes to his life, added to a sense of failure. At Time 1 he admitted initially struggling to restore confidence due to the orchidectomy, which led to him feeling more guarded and vulnerable, particularly around other men.

> '*I suppose you do feel they have taken something away and I'm not quite what I was, not that it matters, but just from a yeah definitely have felt a little bit more guarded and protected, not from a physical point of view, just from a weird mental thing, at times when I don't quite feel as confident as I should do at the moment…….I'm the forefront of everything, chairman of this and that, I can stand there and talk to anybody, but I did feel quite vulnerable, I felt quite as if I was just cowering a little bit and I didn't feel as strong or as puffy as I like to exude myself, so I do feel a little bit weaker…I'm not weak I'm not physically weaker but I just feel like I'm having to prove a point again'* (P10, T1, 41 yrs, Married, Surgery)

While resuming work roles facilitated the process of preserving a normal self; for P10, this was deemed to hinder the process of adjustment, as he attributed self-employment as an added pressure resulting in a quick return to work after surgery. The lack of time to make sense of the event was attributed as a contributing factor to his sense of ambivalence (*'I didn't have the luxury of having too much time off'* P10, T1).

Process 6. Re-establishing a sense of security and relinquishing fears (vs. losing a sense of security and ruminating on fears)

In comparison to others in the sample, P10 seemed to hold on to the life threatening nature of cancer and ruminate on his fears. Despite having early stage disease and treatment with surgery alone, he struggled to hold on to feelings of security over time, feeling increasingly isolated to deal with his feelings in between the safety of getting the 'all clear' at follow-up appointments ('*you've got to deal with it in your own'* P10, T1). This was influenced by ruminating over negative illness beliefs regarding his susceptibility to a recurrence in terms of other cancer types or a recurrence in the remaining testicle, as well as other health risks ('*wait for the next thing to give up'* P10, T2).

> *'what's to say then that if, albeit I had it there, that it's not going to come somewhere else, and why if I've had it there, what's to say that it's not going to go in the other one?…I did sit there and think the other day, what happened if it grew back in the other one, you'd really be in a mess then'* (P10, T2, 41 yrs, Married, Surgery)

By Time 2, while other participants had accepted that their lives may potentially be more uncertain or precarious, P10 increasingly struggled with tolerating uncertainty despite being given survival odds of 92%. This contributed to him losing a sense of security in his future over time which resulted in feelings of sadness and fear ('*I wouldn't say I'm back to total normal, no, not quite, I still don't feel right*' P10, T2).

> *'Mentally it was easier I think at the start, because there was something to deal with, and I'm finding it more emotional now than I did at the start.. it's hard, it is hard to deal with, because you're sad because you had it and you're happy because it's gone, sad, happy, sad, happy, and that's hard to deal with'* (P10, T2, 41 yrs, Married, Surgery)

To reduce the threat of a recurrence, these beliefs led to the adoption of safety behaviours, such as attempts to put on weight, believing this could reduce his risk. This attempt to regain a sense of security in the future was influenced by having a generalised view of cancer, believing that all cancer recurrences have the same symptoms.

> *'I keep putting on weight, because I keep convincing myself if I go there every month and I'm the same weight or a bit heavier…but I don't know whether that's psychological, because you think if I keep the weight up be alright, be fine, people say you've got cancer you get thinner anyway, but it's not always the case, I don't think'* (P10, T2, 41 yrs, Married, Surgery)

The brevity of being treated by surgery alone led to regret over not having any additional treatment, as he felt chemotherapy would have reduced his risk of recurrence. In fact, being placed on active surveillance was perceived as more risky than undergoing chemotherapy.

> '*Sometimes think I wish I'd have [had chemotherapy], not that you want it, but wish I'd have had it to have knocked it right down'* (P10, T2, 41 yrs, Married, Surgery)

Overall, his failure to dismantle the threats led to negative adjustment in the form of greater insecurity, isolation, increased fear and distress, poor self-esteem, a disrupted identity and sense of ambivalent acceptance, as he appraised the disease as being highly disruptive to his life trajectory, especially towards his future.

> '*when I think about [child], I hope I'm going to be around, whereas before I wouldn't, it wouldn't have been hope, I would have presumed and been more confident I was going to be around, you do think, yeah, I'm going to do everything I can to be around, but feels more of a chance than it is maybe, because you've had that little setback'* (P10, T2, 41 yrs, Married, Surgery)

To summarise, comparisons with this case of negative adjustment (P10) further supports the proposed theory of adjustment, demonstrating how the opposing processes led to a negative adjustment trajectory.

Chapter 7: Adjustment in Young Adults with Hodgkin Lymphoma

7.1 Introduction

This chapter will describe the experiences of participants with Hodgkin lymphoma using the framework of the theory of adjustment to cancer. Due to the greater intensity of treatment received by this participant group, a section illustrating the contextual background behind participants' post treatment experiences (section 7.2.1) is also presented.

7.2 Interviews with Hodgkin lymphoma survivors

Hodgkin lymphoma survivors generally encountered much longer and intense treatment regimens than those with testicular cancer. The unique experiences of Hodgkin lymphoma survivors are further presented in the framework of the theory of adjustment to cancer in young adulthood. Comparisons to the testicular cancer survivors are highlighted throughout. Figure 6 illustrates the theory relevant to this sample of participants (highlighted in bold with an asterisk).

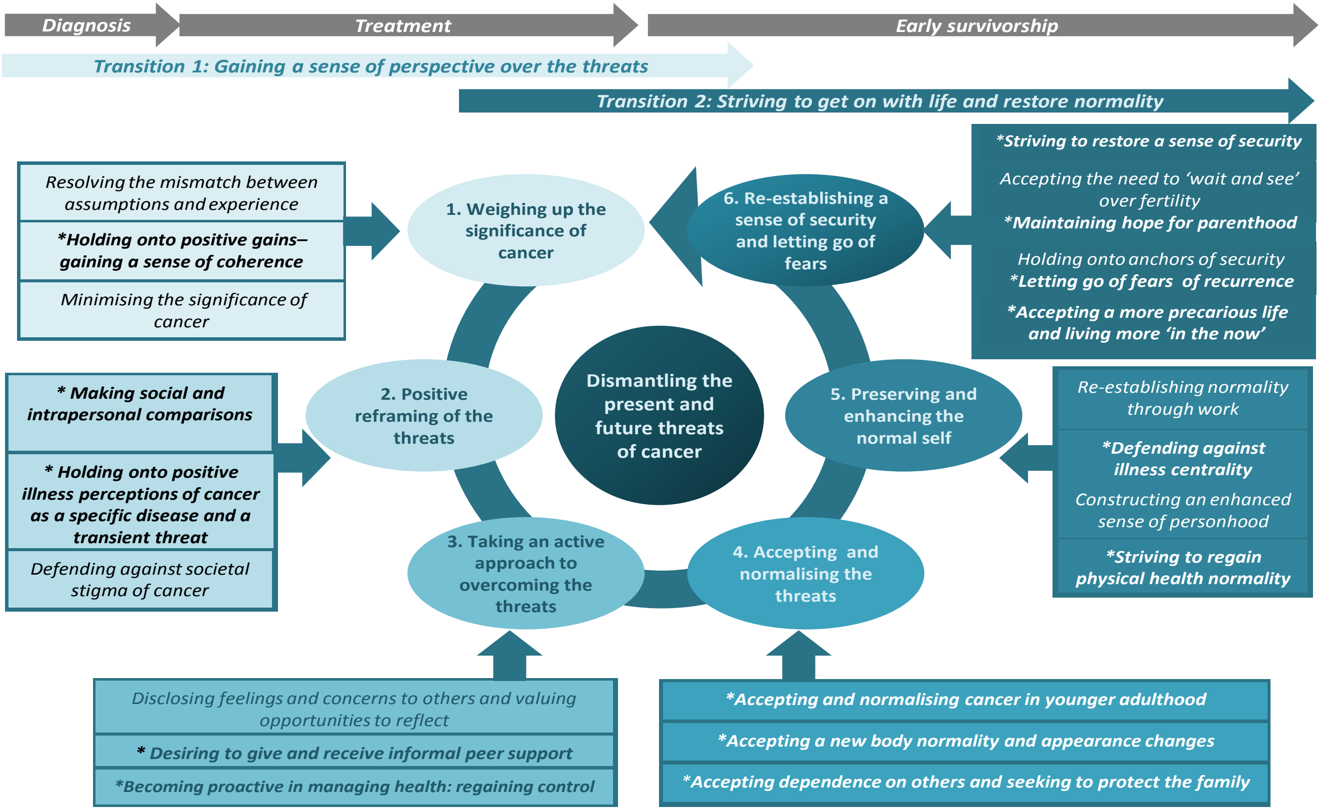

Figure 6: A theory of positive psychosocial adjustment: 'Dismantling the present and future threats of cancer' (relevant to participants with Hodgkin lymphoma)

7.2.1 The context: transitioning out of a state of disorientation and distress

Getting a diagnosis of Hodgkin lymphoma in younger adulthood was often not straightforward, and diagnostic delays were common, as symptoms were often missed by participants and health professionals (*'you ask why do you get pain when drinking and no-one can answer it, the doctor couldn't answer it'* P3, T1). The disease often struck in the midst, or wake, of key life events, such as becoming a parent, moving in with a partner, changing careers, divorce or family bereavement. It was in this context that young adults had to grapple with the diagnosis of Hodgkin lymphoma, which led to a state of shock, distress and disorientation. Participants typically underwent around six months of treatment, often struggling with day-to-day life being on hold, as the diagnosis and treatment period disrupted and stole precious time from the normally industrious period of young adulthood (*'you feel like you're a bit robbed'* P26, T1).

> *'[Treatment] feels like a really long time and it feels like your life is on hold, and everyone else is busy carrying on with things, and you feel as if your, it's like going along a motorway and coming off a slip road and just parking there and everyone else is zooming past and they're having kids and they're getting married and…they're getting promoted and you just feel I can't do anything, I can't do the next things that I need to do in life because I'm stuck waiting for this treatment to finish'* (P6, T1, female, 34 yrs, Divorced, Chemo)

Being a young adult on a cancer ward could leave some feeling '*out on a limb'* in having a disease associated with older adults.

> *'I think if I was… in my 60's or 70's I might be a bit more mentally prepared to be given a cancer diagnosis than I was at 34, so yeah the whole being a young person just feels quite strange'* (P6, T1, female, 34 yrs, Divorced, Chemo)

Participants experienced a range of chemotherapy-induced side effects, notably fatigue, nausea, sickness, alopecia and peripheral neuropathy, which often worsened over the course of treatment, and threatened participants' sense of control over their lives. So, by the end of treatment, these participants often felt both physically and psychologically exhausted.

> *'It just tears you down, it grinds you down*' (P3, T1, male, 35 yrs, Married, Chemo)

In particular, Hodgkin lymphoma survivors found side effects of steroid treatment, including aggression, mood swings, euphoria, insomnia and weight gain, especially challenging. One participant (P3) who experienced a relapse of Hodgkin lymphoma had learned better ways of managing the effects of the steroid treatment by Time 2.

> *'I think I learned to deal with [steroid treatment] a bit more this time, I anticipated what was happening…. I was restrictive of what I'd do, I wouldn't go out, I'd try not to spend money cos if I did I would spend too much, I'd try not to make too many decisions at work that were money related, I'd also even though I'd taken loads*

> *of steroids and I'm up ready to go, I used to take the morning off and just sit down calm and try and let them settle…I learned to manage them a bit better this time'* (P3, T2, male, 35 yrs, Married, Chemo+SCT*)

It was in this context of more intensive treatment that Hodgkin lymphoma survivors sought to adjust to the period following treatment completion.

Transition 1: Gaining a sense of perspective over the threats of cancer

Process 1. Weighing up the significance of cancer

Compared to the testicular cancer patients, these participants appraised the experience of Hodgkin lymphoma as generally more significant in terms of being more threatening and biographically disruptive towards their day-to-day lives, and having a negative impact on their sense of control, relationships, identity and appearance. Some participants evaluated the disease as the most significant life event they had experienced to date.

> '*Pretty major life event frankly, it's kind of up there with like some of the bigger ones…it's my first serious health issue, and at the age of 24 you don't expect serious health issues….that's something you expect like later on, like 20 years down the line, so having a serious medical health issues that could potentially kill me is, yeah, is pretty major'* (P28, T1, male, 24 yrs, In a Relationship, Chemo)

Despite these perceptions, participants generally displayed an overwhelming sense of resilience, often feeling they had coped positively with the experience. In comparison to the testicular cancer sample who often minimised their treatment experiences, these participants evaluated treatment as a long and arduous journey (‘*I seem to get a lot of side effects that weren’t even mentioned’* P24, T1).

> I: ‘*so how did you find [treatment*]?’
>
> 24: ‘*pretty tough to be honest, yeah. [Health professionals] warned me that it was going to be quite a gruelling regime [ABVD] and it is one of the tougher ones… I did get to know quite quickly when I was going to probably start feeling OK again, before I then sort of got hit with it again and went back downhill…’* (P24, T1, female, 37 yrs, Married, Chemo)

Only a few participants felt that the treatment was not as bad as they initially expected.

> *‘nothing changed when I had it [treatment] either, like obviously I went on the sick from work, the chemo was alright like, I didn’t have really no side effects, and everyone said to me chemo it’s bad stuff and you feel ill, I felt great’* (P21, T1, male, 21 yrs, In a Relationship, Surgery+Chemo+R)

A few male participants minimised the seriousness and significance of the disease, as a way of defending against the threat of mortality, which had parallels with some of the testicular cancer patients.

> *'every time you keep speaking to [doctors] about it they're still trying to cure it, they're not even trying to patch me up or just give me a few more years, there still trying to cure it, so that why it feels like it's not that much of a biggie'* (P3, T2, male, 35 yrs, Married, Chemo+SCT*)

The significance of Hodgkin lymphoma was felt to depend on whether the disease would threaten future events or key milestones of adulthood, such as parenthood, so appraisals of Hodgkin lymphoma were not definitive, but an ongoing process.

1. 1 Holding onto the positive gains - gaining a sense of coherence

Due to these appraisals of Hodgkin lymphoma, the process of deriving and holding onto positive gains from the experience was paramount in helping patients dismantle the threats of treatment. This process encouraged perceptions of the illness as a positive, transformative experience, enabling participants to gain a sense of coherence regarding the meaningfulness of the event. Positive outcomes centred on similar key areas to the testicular cancer patients, although Hodgkin lymphoma patients seemed to draw on these outcomes to a greater extent. On completion of successful treatment, some participants felt that, overall, life was better after having cancer due to these positive outcomes ('*it happened for a reason'* P21, T2), despite the negative impact.

> *'to be honest, nothing's changed, if anything its better…cancer can be devastating and it can ruin lives but also I think it's made my life*

> *better and it makes you find out who the true people are'* (P4, T1, female, 22 yrs, In a Relationship, Chemo)

Similar to the testicular cancer sample, participants felt a strong sense of having strengthened attachments to significant others, particularly emphasised by female participants regarding feelings towards their peer group. In this sample, some who were partnered but unmarried gave their partners an '*opt out'* at diagnosis, so knowing that their relationships had survived cancer was strongly held onto as a positive benefit.

> *'I think it improved my relationship, we were very happy beforehand, so I mean it's not as if, but I think.. it's a very odd thing telling your girlfriend you've got cancer…. because I gave her an option out if that makes… like say.. if you don't want to deal with this I understand, and if you want to… we'd been together for about [x] years'* (P28, T1, male, 24 yrs, In a Relationship, Chemo)

Deriving a sense of positive meaning helped these participants to accept the many losses of cancer, such as time lost due to treatment, lost friendships or losses related to fertility and confidence.

> *'Bad bits to it, but there's good bits to it, no point in looking at the bad bits, just the good bits about it really'* (P3, T1, male, 35 yrs, Married, Chemo)

Participants also derived a sense of positive personal growth following cancer. Feeling a better and stronger person made some participants state that going through the treatment had been worthwhile at refining their character (‘*it makes you stronger, definitely’* P27, T1).

> *‘It becomes a big part of your life, and it takes a big chunk of you away I suppose, it changed me for the better…I’m obviously not glad that it happened but in a way I suppose I am a little bit cos it makes you appreciate things, it makes you less insecure and.. whatever I’ve wanted to do in life before I was like oh no I don’t think I should do it, I was like you don’t know what’s going happen so just do it’* (P4, T2, female, 22 yrs, In a Relationship, Chemo)

Importantly, participants felt they had greater self-efficacy for dealing with future challenges, and more confidence in their own abilities (‘*if you can do cancer you can do anything’* P4, T2), as well as greater resilience to day-to-day stress. This was influenced by a sense of pride and achievement in coping positively with cancer (*‘I surprised myself at how I’ve managed’* P24, T1).

> *‘If I can cope with this then, and still be positive at the end of it, then I feel as if I can deal with a lot of other things as well’* (P6, T1, female, 34 yrs, Divorced, Chemo)

In relation to appearance concerns, the perceived loss of vanity and insecurities over appearance were seen as enhancing to self-identity, and similarly to the testicular sample, scars from treatment could add to a sense of unique identity.

> *'I used to be really vain and insecure and now I just go out with the thing of again, f**k it…I'm alive, just have a good time, if somebody fancies me great if they don't, ah well never mind, at the end of the day my hair will grow back it will be long again….you lose your hair, so what, it grows back, I've got a scar here but I don't look at it and think oh my god I'm scarred, I look at it and think there war wounds, they tell a story'* (P4, T2, female, 22 yrs, In a Relationship, Chemo)

Process 2. Positive reframing of the threats of cancer

2.1 Making social and intrapersonal comparisons

In a similar way to the testicular cancer sample, Hodgkin lymphoma patients made social comparisons as a way of reframing the disease as less threatening. In particular, making comparisons to other '*worse cancers'* helped form participants' perceptions of themselves as *'lucky'* (P6, T2). Social comparisons helped participants to better cope throughout treatment and beyond to defend against feelings of distress, self-pity and fear, and gain a sense of perspective.

> *'if you're gonna get a cancer it's the cancer to get, which is a bit odd way of looking at it, but you know I feel very fortunate that I've got this sort of cancer'* (P22, T1, female, 39 yrs, Married, Chemo+R)

This was particularly salient for P3, who underwent a stem cell transplant for relapsed disease.

> *'being lymphoma you still look at it and weigh it up against well at least it isn't lung cancer, or bowel cancer or at least it isn't something else, not that lymphoma can't kill you, it's just that there's more chance of them fixing that then there is of fixing lung cancer or other cancers.....sometimes it humbles you, you walk in to the hospital thinking why me and it's not fair, and then you see a couple of parents pushing a 3 year old... so on that basis you think don't be so selfish*' (P3, T2, male, 35 yrs, Married, Chemo+SCT*)

Whilst some rejected the idea, several females in this sample had been active in attending support groups, and discussed the negative impact of downward social comparisons when meeting other Hodgkin lymphoma patients who had relapsed. This threatened their positive perceptions and increased fears of treatment side effects due to the diversity of experiences of Hodgkin lymphoma treatment.

> *'a lot of the people who went to the support group were people who had had complications or who had had relapses or problems so I ended up speaking to someone who was really nice but he'd had a relapse and he'd been through really difficult treatment and that really scared me cos I started thinking oh this could happen to me as well, and so I came away from the support group thinking 'ahh ok', it's not necessarily as straight forward as I hope it's going to be I could end up with a relapse I could end up having to go through a*

> *different type of treatment so that kind of shook me up a bit'* (P6, T1, female, 34 yrs, Divorced, Chemo)

Getting the balance right between being informed and 'knowing too much' in the case of P3 was important.

> *'So it's good to speak to [peer survivors], well it's good and bad you try and compare it…sometimes you ask too many questions like I was asking about the effects of when you go in for the high dose [chemotherapy] and the transplant, some of it was useful, some of it I'd have rather not known about*' (P3, T2, male, 35 yrs, Married, Chemo+SCT*)

Peer support could also, however, help facilitate upward social comparisons with long-term survivors as role models for reassurance and hope that life would eventually return to normal.

> '*having examples is really reassuring, not just maybe reading it, but having an actual life example, you will be normal again, so that's really good'* (P26, T1, female 26 yrs, In a Relationship, Chemo)

2.2 Holding onto positive illness perceptions of cancer as a specific disease and a transient threat

Holding positive illness perceptions towards Hodgkin lymphoma, particularly regarding the curability of the disease dismantled initial fears over mortality. Some participants even alluded to feelings of safety and relief once hearing their diagnosis, especially as diagnostic delays were common. Hodgkin lymphoma could be initially perceived as ‘just a disease’ rather than a type of cancer, although these perceptions were not enduring.

> *‘At the beginning I even thought.. it’s not like a cancer, it’s just a disease, I didn’t even name it’* (P26, T1, female 26 yrs, In a Relationship, Chemo)
>
> *‘all you want to know is that you’re not going to die, and you can take the treatment, you almost feel quite safe once they’ve told you what type of cancer you’ve got and once you’re having treatment….but thank God for that, they know what it is and they’re gonna do something about it’* (P3, T1, male, 35 yrs, Married, Chemo)

In line with the testicular cancer sample, perceiving Hodgkin lymphoma as a specific and acute disease helped dismantle fears over mortality. Perceptions of Hodgkin lymphoma as a *‘sort of a boxed cancer’* (P22, T1) in terms of an illness that was transient and had a definitive end helped reframe the illness, as it was perceived in a more positive way compared to cancers such as non-Hodgkin lymphoma, which was seen as having a more enduring trajectory.

> ‘*if it was breast cancer and I was at this stage I’d probably be a bit more worried….whereas cos it’s sort of a boxed cancer, I think it’s easier to cope with… as in it’s a diagnosis, you have your treatment, it’s likely to have worked, and that will be it, whereas non-Hodgkin lymphoma is an ongoing and.. other cancers are…myeloma is ongoing’* (P22, T1, female, 39 yrs, Married, Chemo+R)

Holding onto these positive perceptions helped patients to cope throughout the challenges of treatment, particularly if this was reinforced by health professionals.

> *'knowing that it's very curable has always made a big difference…so that's probably a bit factor knowing that we can deal with it makes it worthwhile going through the treatment cos you know you can lead a normal life afterwards'* (P11, T1, male, 23 yrs, Married, Surgery+Chemo)

Participants who were parents attempted to shape positive illness perceptions in their children regarding the distinctive and acute nature of Hodgkin lymphoma, in order to reduce their fears. In P3 who had a relapse, holding onto the curability of the disease was instrumental in helping him retain a sense of perspective over his diagnosis.

> '*when I'm down and not got any confidence, I get the consent form out and there's 3 different options and the first one has got cure in the sentence, so you look at it and think that's good enough…it was the best option of the 3 on this consent form so you take that as a small gain, and think we'll move on from that'* (P3, T2, male, 35 yrs, Married, Chemo+SCT*)

Process 3. Taking an active approach to overcoming the threats –utilising external resources and support

3.1 Becoming proactive in managing health and wellbeing: regaining control

In addition to eliciting emotional and practical support from friends, participants were often proactive in seeking and utilising support from alternative sources, such as complementary therapists, internet forums or cancer centres. This helped them to regain a sense of control through taking charge of their own wellbeing, and increased self-efficacy at managing treatment side effects. Some participants exercised control through changing their diet or using relaxation techniques, as they found information by health professionals on self-management inadequate and wanted to take an active rather than passive coping approach.

> ‘*the hardest thing for me was going in to hospital and asking what can I do for myself, because I like to kind of take charge of situations, I’ve always been very interested in nutrition and exercise, and things that I can do to support my body to get through this treatment and fight this cancer, and I was just told there’s nothing you can really do… I think it would help if people felt they could do something, were getting some good information about how to look after themselves’* (P24, T1, female, 37 yrs, Married, Chemo)

Participants often praised the care they had received, especially from the CNS. Female participants in particular strongly valued the information given by the CNS as some had signposted them to sources of support for childcare or financial support. Some also sought information online, however expressed divergent views towards online information, which could be perceived as threatening or helpful. Official online sources were valued, particularly websites such as Cancer Research UK and the Lymphoma Association. While internet forums were valued in some, cancer '*horror stories'* could increase fears in others.

> '*I stayed very much away from online stuff, because I felt… it's not verified at all.. it's too easy for it to be full of crap, some I decided not to bother…. if anyone asked me about it I would tell, either send them to the lymphoma one or the Macmillan one, I said don't bother looking at anyone's blog, or don't bother looking at anything additional, because it just won't help you… it was so easy to contact them by phone or e-mail, what was the point in getting the wrong information'* (P28, T1, male, 24 yrs, In a Relationship, Chemo)

Other participants weighed up the pros and cons and generally praised online information, as hearing about others experiences helped to normalise the disease, and sharing advice with other young mothers for instance, increased perceptions of the manageability of Hodgkin lymphoma treatment.

> '*So hearing from other mums with young children really helped. There's probably only about three or four other women who posted messages, but it meant so much…'* (P24, T1, female, 37 yrs, Married, Chemo)

3.2 Desiring to give and receive informal peer support

Similar to the testicular cancer sample, participants strongly valued informal emotional support, particularly from both cancer and normal peers, and opportunities to reflect on the experience. Sharing experiences with other cancer survivors, especially other younger adults, helped patients to gain perspective through normalising the experience and giving them hope for a restored life. Participants met other peer survivors through their existing social networks or during treatment.

> '*It's helped me speaking to the 3 or 4 people I know who've had lymphoma and [they] have been similar sort of ages and now they've dealt with it, and it gives you a bit of hope as well, cos before I spoke to them the only people I knew with cancer have mostly died or had really bad cancer, I didn't realise there was millions of different types, you speak to people with lymphoma it's not that bad, but that's only through talking to other people'* (P3, T1, male, 35 yrs, Married, Chemo)

Again, as with the testicular cancer sample, the idea of peer mentoring or a 'buddy' scheme with other Hodgkin lymphoma survivors was raised as potentially helpful, especially if they were matched on age, disease and demographics variables such as parenthood. This was particularly the case if they were unable to meet other young cancer patients during treatment, and felt a strong sense of difference as a young adult on a cancer ward.

> '*If I could have been linked up with someone maybe who'd gone through treatment in a similar situation as me, with young*

> *children…that would have been really useful'* (P24, T1, female, 37 yrs, Married, Chemo)

In those who attended support groups, they valued the group solidarity and '*being in the same boat'*. In fact, helping other young adults through support groups who were struggling helped participants derive a greater sense of positive meaning from the experience.

> *'I feel happy that I can help someone else, in the sense of telling them my experiences, so I think I feel good for helping and explaining things…. so I feel really thankful, and if I can give something back to someone else and help someone else then I think that's a positive thing, makes me feel better'* (P27, T1, female, 37 yrs, Married, Chemo)

While some participants were active in seeking out support from cancer based sources, others preferred to utilise the support from their own existing social networks, preferring normal conversations and fearing being '*dragged down'* (P22) by too much contact with other patients ('*you've got your mates'* P4, T2). The idea of contact with other peer survivors threatened their desire to maintain a normal identity and be independent.

> '*sometimes when people are in the same boat as you, you don't necessarily want to talk about it, you sort of want to talk to somebody who's not in the same boat who will just listen and not say oh yes I've done that….I've just trolled along and been me, and I don't know I just found that the thought of the idea of sitting around with a load of people who've got cancer isn't my idea of fun*

> *[laughs] it doesn't necessarily support me, cos it will highlight things that perhaps I'm not thinking about, and are oblivious to, which I could start worrying about*' (P22, T1, female, 39 yrs, Married, Chemo+R)

Others had sought counselling through cancer charities, which was found to be beneficial, in a similar way to the research interview. For one male participant (P3), the research interviews were utilised as one of the few opportunities to reflect on the experience which helped him to box the experience away, as he felt it was easier talking to strangers than his wife or close family.

> '*you've got to talk to people, and you find them in strange places as well, it won't necessarily be talk to your wife, talk to your parents, talk to your siblings, cos I couldn't have these conversations, the only people in my life that I've talked to about it is obviously yourself, and the woman who come round doing the massage.....get it off your chest, is amazing just being able to talk to someone get it off your chest, you can put it in a box and get on with it again'* (P3, T2, male, 35 yrs, Married, Chemo+SCT*)

Male participants in particular, emphasised their preference in finding their own way to self-manage their emotions. Similar to some men in the testicular cancer sample, there was a tension between wanting to cope independently versus recognition of their need for more psychological or '*moral'* (P11) support. Yet, despite advocating the need and importance of psychological support ('*psychological support I think is more important* *than the medical support'* P3, T1), these men were reluctant to seek help, and some had even turned down offers of counselling. One participant (P3, T2) who had relapsed also struggled with raising the issue of depression with the GP, going under the guise of another issue. At Time 2, he questioned whether he should have accepted offers of psychological support initially, attributing the non-uptake of support to the lack of positive results.

> '*I think the only reason I'm in a dark place is because I want somebody to tell me that they've sorted out everything that's wrong, and I know they can't do that, so at the moment I think any type of counselling it would help but it's not gonna sort me out, the only thing that can sort me out is getting to [scan results] and someone telling me what we've done has worked and you're ok for the time being and that would be good enough, and I think if I'm still down after that then I've got no excuses but to go back and take the help'* (P3, T2, male, 35 yrs, Married, Chemo+SCT*)

Men valued having support normalised or not labelled as psychological support, such as informal professional support given by nurses on the ward. Some discussed the need for an assigned care worker or coach, as a form of support that wouldn't threaten their ideals of being independent. For this reason, some male and female participants felt that counselling should be offered as part of the care package.

> *'I think there's a bit of a stigma to the term to have counselling for it, but I do think that it would probably be useful to talk to sort of someone like that I suppose…I think we could have just done with*

> *more moral support and reassurance than anything physical*' (P11, T1, male, 23 yrs, Married, Surgery+Chemo)

> '*at any point it would have been nice to have counselling really on hand, either professional counselling or just a person who was volunteering to talk to you*' (P6, T2, female, 34 yrs, In a Relationship, Chemo)

Summary of transition 1

For these participants, the first challenge was to come to terms and make sense of the diagnosis and often intensive treatment they had received. This involved transitioning from a state of disorientation and distress during diagnosis and treatment to gaining a sense of perspective over the threats of Hodgkin lymphoma ('*just trying to put it in perspective really'* P3, T2).

Transition 2: Striving to get on with life and restore normality

The transition of s*triving to get on with life and restore normality* was central in facilitating the shift from a state of uncertainty and insecurity following treatment completion to a greater sense of security and confidence. This transition was particularly challenging for this group of survivors.

Process 4. Accepting and normalising the threats of cancer

4.1 Accepting and normalising cancer in young adulthood

The process of accepting Hodgkin lymphoma and the suffering it caused as something that was ‘*part of life*’ (P22), and normalising the experience of cancer in young adulthood helped participants to transition towards normality.

> *‘I wouldn’t say I’ve had a journey to get me where I am… we all have different roads to travel and sometimes they’re uphill, sometimes they’re down freewheeling, sometimes you have to pedal hard to get up the hill, and it’s all part of life. You can’t change life, you can’t say this should be happening to somebody else, because one in three of us will be affected with cancer, and that’s life.. and it’s just how you deal with it, and there are crap times, but there are really good times that you’re blessed by it’* (P22, T2, female, 39 yrs, Married, Chemo+R)

Accepting the diagnosis helped participants to avoid self-pity and facilitate a ‘getting on with it’ approach to dealing with the adversities of cancer, and the threat to their day-to-day lives.

> *‘I think I coped quite well… I ain’t the sort of person.. when they diagnosed me I was like I got it, that’s it, what can I do, just go with the flow kind of thing, that’s the sort of person I’m like*’ (P21, T1, male, 21 yrs, In a Relationship, Surgery+Chemo+R)

Maintaining hope in their future lives was helped by the acceptance of the temporary suffering they had experienced.

> *'I know that it's temporary, or maybe not, the thing is you don't know, it may come back, but I don't like to think about it, because I can get other illnesses, you just have to deal with things ... and just accept that, accept them, and it is like it is, you've been probably a bit unlucky, like in a card game, didn't get the best cards maybe, but you may still win [laughs]'* (P26, T1, female 26 yrs, In a Relationship, Chemo)

Normalising cancer as an event affecting multitudes of others' lives also helped them to accept the timing of cancer. Personality traits, such as being pragmatic and optimistic, seemed important in this process.

> '*It's just being real.. cancer does affect one in three of us and I can't rule me out of that, it's not one in three of you, it's one in three of us, and other people are in lots of worse situations, so just being a bit pragmatic and also a bit gun hoe and oh yeah I'll be fine [laughs]'* (P22, T1, female, 39 yrs, Married, Chemo+R)

Despite the fact that the diagnosis often occurred during or following major life events, a few participants even discussed the timing of having Hodgkin lymphoma in young adulthood as advantageous, in terms of having a greater chance of survival, which facilitated acceptance.

> *'I think having it young is an advantage such as survival, fighting it.....cos I think if your young...you've got more go in you, and*

> *you're body's young so it can take a good beating from chemo, so I think having it young... I wanna say you're lucky, cos you're not lucky to have it at all, but you're lucky that you're young so you can fight it'* (P21, T1, male, 21 yrs, In a Relationship, Surgery+Chemo+R)

> *'I'm quite glad I had it when I did because I'm glad [child] won't be able to remember it'* (P4, T2, female, 22 yrs, In a Relationship, Chemo)

Participants who had not yet achieved parenthood didn't share this view, nor did those whose career plans were threatened, expressing fears of future life plans being affected by the stigma of their cancer history, which could hinder acceptance of the disease.

> *'so there's the work and career the way it influences that, there's the whole fertility thing, there's the appearance thing... there's indirect things like insurance for example...and even things like getting mortgages, I think all of that is gonna be affected by having to say yes I have had cancer in the past'* (P6, T2, female, 34 yrs, In a Relationship, Chemo)

Those who had not experienced initial visible signs or symptoms of Hodgkin lymphoma could struggle with a sense of ambivalent acceptance of the disease, similar to some of the testicular cancer survivors. This seemed to occur when patients had the disease in their chest area, without the presence of lumps, which were associated with having cancer. One participant (P3), who underwent intensive treatment for relapsed Hodgkin lymphoma, even questioned his authenticity as a cancer patient, due to the invisible nature of his disease.

> *'You expect people to have operations to get it cut out, it's cos it's not physical and it's not something I can see, you kind of think it's not happening, you sometimes wake up and think am I dreaming it? It still doesn't feel like I've got cancer, you still imagine cancer to be something different to what I've got ...I've probably got a lump but it's in my chest so I can't feel it or see it or touch it, I get side effects from it but not directly to do with that, so sometimes it feels like I'm a cheat cos it feels like I don't have it'* (P3, T2, male, 35 yrs, Married, Chemo+SCT*)

4.2 Accepting a new body normality and appearance changes

Changes to appearance were sometimes paramount concerns of Hodgkin lymphoma survivors during and shortly after treatment. Alopecia could be experienced as the most difficult and distressing effect of treatment, especially for female participants ('*the biggest thing is the hair'* P6, T1). A positive transition of accepting appearance changes was characterised by a range of processes, including; taking control, reframing appearance as insignificant, deriving positives from appearance changes, concentrating on living more 'in the now', using humour and finding ways of maintaining identity. Some female participants took control over the threat of impending hair loss by shaving all their hair off at the beginning of their chemotherapy course.

> *'It was my decision to do it when I did it, I felt like I had control over it, so it didn't bother me. It was a relief when I decided to shave it all off, because it was coming out so much I just thought, it looks a mess anyway, why am I trying to keep it, so I had a grade three all over and I just felt so much better for doing that'* (P24, T1, female, 37 yrs, Married, Chemo)

Although to a lesser degree, male participants could be concerned over appearance changes, particularly any visible differences that altered their self-image, such as losing facial hair and weight gain. There was a sense that these concerns were unjustified due to their gender.

> *'I was more concerned with losing my hair, it thinned, I didn't lose my hair, but it thinned so I couldn't have do nothing with my hair…and when I did I looked like that 50 year old man who's just started receding but who's trying to cover their hair'* (P21, T1, male, 21 yrs, In a Relationship, Surgery+Chemo+R)

> *'I'm more confident now my hairs grown back, that was an issue, I didn't think it would be an issue…I'm a bloke so it shouldn't really matter'* (P3, T1, male, 35 yrs, Married, Chemo)

Humour was used over appearance issues with peers and spouses, which helped maintain a 'normal' self and minimise the experience of being bald.

> *'me and my mates used to make jokes about it… me and [partner] was making cakes once and was having a cake fight and he put [chocolate spread] on the top of my head and licked it off when I*

> *was bald, and covered my head in it, and it was just making a laugh of it, he'd come in and slap the back of my head or once [friends] came in with a present for me and it was a bottle of Mr Sheen and they said you could shine your head with it, and a duster and we used to just laugh about it'* (P4, T2, female, 22 yrs, In a Relationship, Chemo)

For those in relationships, reassurance and attention from partners was paramount and helped them accept and adjust to these changes.

> '*my husband has always told me, which has probably helped with the body image and self-image, he's always said you look great with no hair, you should always have a shaved head, so ... that's got to make a difference, so I've not cared, and going through the treatment and feeling as bad as I've felt through the treatment, losing my hair and things like that was the least of my worries'* (P24, T1, female, 37 yrs, Married, Chemo)

Those who were parents attempted to lessen the impact of their appearance changes on their children, through involving children in shaving their hair or choosing headscarves, as well as by cutting hair gradually to allow children to adjust to the changes.

> *'I had it cut short, and then I had it... even shorter, and then it was just starting to come out... I made a joke with my daughter, I look like Jessie J [pop star], and we're going to go and choose some headscarves together'* (P27, T1, female, 37 yrs, Married, Chemo)

Some females strove to maintain their sense of femininity in order to counter act the threat to normality regarding their body image (‘*I became more interested in makeup, nail polishes..’* P26, T1*)*. Some reframed appearance changes in a positive way, feeling it was insignificant in light of the threat to mortality. Despite these strategies, some participants, particularly females, could struggle with accepting and adjusting to appearance changes and with confidence in ‘going back out into the world’. Some grappled with distress over the losses of femininity, identity, confidence and perceived sexual attractiveness.

> ‘*It’s probably one of the most depressing things, changes a lot, a lot of people lose their hair, I guess you get used to it, but not really… You lose your eyebrows, your hair, you just don’t look, I don’t look like a girl anymore. I like to be a girlie girl, all those things together can get you down’* (P26, T1, female 26 yrs, In a Relationship, Chemo)

For one participant (P22) despite initially being unconcerned over appearance changes, by Time 2, was struggling to accept a changed appearance. Although her hair had grown back, it had changed texture and style, which threatened feminine identity and lowered self-confidence.

> *‘The one thing I have struggled mega, mega big time with is my hair, because it was dead long [and] straight, and now I just look like I’ve been pulled through a hedge backwards the whole time…I think having my hair like this feels like it’s a mess, so I don’t feel smart, so I don’t feel confident, because my hair feels a mess, then I feel a*

> *mess… it's just taken everybody in the family really [partner] and the boys a long time to adjust to it, and I just look in the mirror and just think, it's not me..'* (P22, T2, female, 39 yrs, Married, Chemo+R)

In the single participant (P6), at Time 1, hair loss affected feelings of confidence towards re-entering the dating scene. The development of a new relationship by Time 2 helped to lessen these initial fears.

> *'[Before cancer] I had lots of comments from men saying 'oh your hair is beautiful' and when that's taken away from you that's a big thing, and I feel like now, my [relative's] saying to me 'oh why don't you try online dating again?' and I feel like I can't do it cos I haven't got my beautiful long hair that I had and I don't feel confident at all about going out on a blind date with somebody'* (P6, T1, female, 34 yrs, Divorced, Chemo)

4.3 Accepting dependence on others and seeking to protect the family

Participants initially had to adjust to threatened relationships and accept being dependent on others for support, often to a greater extent than the testicular cancer sample. Some lost friends who had been unable to cope with their diagnosis, although this was often weighed against developing closer attachments to other friends. Due to extended treatment side effects, such as fatigue, female participants in particular, needed to seek out a lot of practical and emotional support, especially regarding childcare, from their friends, families or cancer charities. Accepting support and their temporary dependence on others improved their feelings of being able to manage the impact of the treatment, helped them maintain a sense of normal life for themselves and their children, and reduced concerns over being a 'good' parent throughout treatment and beyond. Participants reflected that this dependence led to an enhanced sense of belonging to others through strengthened and more secure relationships ('*bringing my family closer together'* P24, T1).

> '*So nice to have that bit of help, because there were days [during treatment] where I just couldn't have done anything or looked after them, and I was thinking oh God, I'm a really bad mum, but I just can't do it, I'm just really tired, really feel ill. So it was so good to have that sort of support and backup*' (P27, T1, female, 37 yrs, Married, Chemo)

Conversely, adjusting to greater dependence on others seemed more challenging for male participants, who sought to maintain their independence, so struggled with balancing their desire to protect others with their need to accept dependence. One male participant (P28) struggled to cope with prominent feelings of guilt at the diagnosis, but eventually adjusted and learned to accept the shift in temporary role from supporter to being dependent on others throughout treatment and initially afterwards.

> '*I felt very, a lot of shame and a lot of guilt, because I felt like I was letting everyone down, because I've always felt like, I'm a big brother, and I feel like I have to look after people, that's my role, but I realise I couldn't do that anymore. So yes, so it was a massive*

> *psychological shift to go from someone who was...someone who looked after, to someone who had to be looked after…..over time you accept that'* (P28, T1, male, 24 yrs, In a Relationship, Chemo)

In one case, strained marital relationships were felt to be impacted by the side effects of steroid medication, and were felt to contribute to family disputes. Therefore, rather than a sense of greater closeness to others, this participant described a sense of emotional distance in his marriage, which was exacerbated by Time 2. He was hopeful that this would improve over time, and sought support through cancer peers.

> '*It's affected our relationship I suppose, it's strained it, yeah, it's really affected the wife'* (P3, T1, male, 35 yrs, Married, Chemo)

Process 5. Preserving and enhancing the normal self

5.1 Defending against 'illness centrality'

Hodgkin lymphoma treatment was generally more disruptive to patients' lives, and so seemed to threaten patient's identities to a greater extent than the testicular cancer treatment. Participants strongly defended against 'illness centrality' throughout treatment and beyond, which helped them preserve a normal self.

> **'***Cancer won't define me as a person.. it will alter things'* (P11, T1, male, 23 yrs, Married, Surgery+Chemo)

Some described deconstructing the threat of Hodgkin lymphoma, as a form of defence against the stigma of being a cancer patient ('*don't treat me like*

I'm dying' P4, T1), as one participant discussed replacing the word cancer with the term '*the gremlin'*.

> *'I never liked to call it cancer, that's why we called it a gremlin, as funny and as stupid as it sounds cos to me it was just to me it was just I've just gotta get rid of something, I'm a bit poorly now but I won't be poorly forever, I never wanted to be treated like someone….I've always said to everybody 'treat me the same', I said 'cos in my mind I'm not ill'* (P4, T1, female, 22 yrs, In a Relationship, Chemo)

One participant avoided talking about Hodgkin lymphoma as a cancer at all, as this seemed safer and less threatening than telling others he had cancer, possibly reflecting a sense of denial over the threat.

> *'I can't say cancer, I've got to say lymphoma, cos I think people might think oh I wonder what that is, and it just sounds, to stand there and say I've got cancer, it seems a bit, I dunno I think cancer's quite a bit, it covers quite a few things really, I dunno if that's a bit of denial'* (P3, T2, male, 35 yrs, Married, Chemo+SCT*)

These participants described a strong desire to keep the disease experience in the background of their lives.

> '*I didn't want to just sit here and… I didn't want to always talk about cancer with people, I wanted it to be something that was going on in the background'* (P28, T1, male, 24 yrs, In a Relationship, Chemo)

For one participant (P4), the determination to preserve a normal self meant she went to the extreme of taking risks, such as going to public places whilst immunocompromised. This might have been due to a lack of understanding of the life threatening nature of infections during chemotherapy.

> *'I wasn't gonna let [cancer] stop me doing what I wanted to do, and I never did, I went down to the seaside.. I did everything I would normally do, went out for a friend's birthday, went out for meals, I went out clubbing one night, I didn't drink I drove, obviously the only things I couldn't do was things like swimming and stuff like that, but I just thought if I was feeling fine, why am I gonna waste 6 months in case I get an infection, well sorry I've already got cancer it can't get much worse than that can it, apart from being told you're gonna die, I might as well risk getting an infection rather than stop living my life'* (P4, T1, female, 22 yrs, In a Relationship, Chemo)

Participants with children strove to normalise treatment regimens and thus minimise disruption to their children's lives, emphasising the importance of protecting their children from distress. This was felt to be achieved through providing reassurance, normalising treatment effects and maintaining family time and normality throughout treatment and beyond, so participants often felt children adjusted quickly. This quote illustrates how one participant strove for normality in her family life, through openly talking about the effects of treatment with her child.

> *'I was radioactive... so you're not meant to be in close proximity to children and I was thinking I can't send them to different rooms,*

> *[child] was like I can hug you now, he went 'night night radioactive mummy'...so we've been sort of fairly obvious'* (P22, T1, female, 39 yrs, Married, Chemo+R)

Following treatment completion, some rejected being part of the 'remission society' (described previously as a place between health and illness where patients are "*effectively well but could never be considered cured*" (p. 163) (Frank, 1995)) and wanted to reclaim their 'normal' identities. Yet for some, this conflicted with the knowledge of having a permanent label of having had cancer (*'like a label for life'* P22, T2). In particular, participants disliked having to wear an irradiated blood tag, (which had to be worn in case an emergency blood transfusion was ever needed) perceiving it as a reminder of illness.

> '*I think it's one of those, I'll always have that label, even if after five years they discharged me, like they quite often do, you know you've still got the label, and the chances of it coming back are obviously higher than having it for the first time....and that worries me a bit.. so I think just long-term, I've always called that label now... but it's more the having to wear this [irradiated blood tag] now that I really don't like'* (P22, T2, female, 39 yrs, Married, Chemo+R)

While another participant (P27) considered whether returning for follow-up appointments would be an unwelcome reminder of illness and hinder their quest to move on.

> *'I'll see how it goes, it's nice to be monitored for now, because I want to make sure if it is going to come back, because I know it can,*

> *that it's caught quickly and dealt with, but then a year or two down the line I might be really fit and well and think ooh, I'm not sure I want to keep going back to hospital, partially to be reminded of it all when I'm trying to move forward'* (P27, T1, female, 37 yrs, Married, Chemo)

Therefore, participants valued casting off reminders of the illness as helping them to get back to normality and disassociate from their cancer experience and the stigma of the disease.

> *'getting rid of the daily reminders, the medication, when they cut the medication down from 3 or 4 times a day to twice a day, less drugs, less reminders really, the hair unfortunately is a bit of a reminder, but I'd imagine in a few weeks' time once I see signs of that growing back that's another thing I can forget about as well'* (P3, T2, male, 35 yrs, Married, Chemo+SCT*)

While some participants initiated changes to their lives, others strove to preserve a normal self through maintaining their normal working lives, which seemed of more importance to male participants, who often worked part-time during chemotherapy, especially during initial cycles ('*the illness is an inconvenience'* P3, T2).

5.2 Striving to regain physical health normality

Participants also strove to regain a normal body self in terms of their lost physical fitness, vitality and strength ('*it was great just to feel part of the world again'* P6, T1). For instance, treatment-related fatigue culminated in feelings of being in an '*aged*' body.

> ‘*In the middle of the treatment I really felt down, because suddenly I felt really out of strength, I felt like… I’m in a young person’s body but I have as much strength as 70-year-old’* (P26, T1, female 26 yrs, In a Relationship, Chemo)

Over Time 1 and 2, participants felt encouraged by small but significant improvements in their activities, and valued witnessing the return of feelings of vitality over time and being able to do increasing amounts of activities (‘*I’m on the up and I feel so much better’* P27, T1). This process often involved setting goals and re-establishing exercise regimens to lose treatment-related weight gain and increase fitness, as well as holding onto the hope for a restored body normality, which took a great deal longer than in the testicular cancer survivors.

> *‘I use to think to myself yeah I might be bald and I might be fat now, but I’ll get my hair back and I’ll get my body back cos I’m one of them people if I want something I go out and get it, and I’m quite strict with myself’* (P4, T1, female, 22 yrs, In a Relationship, Chemo)

Some maintained exercise regimens for the majority of treatment, and so were able to preserve a sense of physical wellbeing for some of this period. For these participants in particular, they felt fatigue levels had returned to normal by Time 1. By Time 2, while some participants felt they were back to normality in terms of physical functioning, others found that fatigue took longer to resolve. Participants adjusted to this through accepting these temporary limitations and this ‘new normal’ physical self, as well as learning the importance of pacing their activities. This could include ongoing fatigue or having a lowered immune system for example.

> *'I'm still tired, but that's just me I think. I'm a lot tired more than I used to be, not as tired as when I was on chemo and stuff, but it's just me! But yeah, I can do anything now…I'm back to normal'* (P21, T1, male, 21 yrs, In a Relationship, Surgery+Chemo+R)

This sample in particular discussed the difficulty of knowing '*what is normal'* in their physical recovery after treatment completion, which heightened fears over a recurrence and a sense of lowered confidence in their body. They were often unsure of the duration of ongoing symptoms and side effects, and felt information in this area was lacking or vague from health professionals, so wanted to know what constituted a 'normal recovery' trajectory.

> *'you want someone to say well this is what usually happens this is how long this will take to recover, I mean I haven't got a clue how long it takes to recover from having chemo …. if someone said oh that's normal you should expect that you wouldn't waste the rest of your day worrying about it, but no-one's really said anything about it you kind of worry, it's not so much the shortness of breath it's the worrying about the shortness of breath .. will it get better'* (P3, T1, male, 35 yrs, Married, Chemo)

Some participants wanted to know whether symptoms would be short-term or permanent.

> *'it would be nice to have an idea of how long certain lingering side effects might take before they go, because I've been getting really bad tinnitus in my ears… and I had neuropathy throughout my chemotherapy treatment, and.. you wonder, are my ears going to ever go back to normal? Is it always going to have, am I always going to have this horrible ringing?'* (P24, T1, female, 37 yrs, Married, Chemo)

Process 6. Re-establishing a sense of security and relinquishing fears

6.1 Striving to restore a sense of security

Psychological difficulties after treatment completion were particularly prominent for Hodgkin lymphoma survivors. Participants transitioned from a sense of relative security during treatment to greater vulnerability once they were discharged. While some felt times of emotional distress were generally limited, others struggled psychologically during this time, particularly with losing a sense of certainty and security in the future. So participants sought to restore and adjust to cancer losses, which varied between participants, and included the loss of confidence, sense of security, and loss of both medical and peer support.

> *'nothing is certain anymore, and even when they say this treatment gets really positive results you're never quite sure and even when you're in remission there's always a chance that it could come back so your suddenly kind of faced with thinking about your life that you might not have… and have to look at everything differently so it's*

> *like a bit of a wakeup call, it's like someone slapping their fingers and saying come on your not gonna live forever you might not live until next year'* (P6, T1, female, 34 yrs, Divorced, Chemo)

Participants often felt de-stabilised and disorientated by the loss of treatment 'safety blanket', and some felt treatment came to an abrupt and sudden end (*'you were kind of left on your own really'* P3, T1). This resulted in a lack of preparedness for life after treatment, particularly towards practical issues, such as knowing when to stop medication.

> *'I expected perhaps a little bit more information from them spontaneously about what would happen next, and what sort of medication I should take, but I had to ask for all of that'* (P6, T1, female, 34 yrs, Divorced, Chemo)

Support from the CNS tailed off over the treatment trajectory for some participants, who wanted more contact with them during the middle and end phase of treatment, particularly more reassurance over side effects.

> *'I think when you start there was a lot of attention to detail, there was a lot of help and support…but at the end it would have been nice to perhaps have seen one of the nurses and had a chat and sort of said well, I've come to an end but I feel like this, explain about things and have had someone to have talked to..'* (P27, T1, female, 37 yrs, Married, Chemo)

Some discussed the need for more support between finishing treatment and their next follow-up appointment, which could be months' later, to reduce their feelings of being *'abandoned'* (P28).

> *'It felt like you were just kind of sent off back in to the big wide world, but because of all the lingering side effects, especially straight afterwards as well, like still feeling really bad.. it felt as though it was maybe a little bit too soon. I think it would maybe be good to have another appointment scheduled in, because my next appointment I would have gone [for 4-5 months] without having an appointment'* (P24, T1, female, 37 yrs, Married, Chemo)

Others were unsure if they needed extra contact with health professionals, but emphasised the importance of timely information that they would have wanted at their last appointment, rather than having to find this information out themselves. They felt this could have better prepared them for the first few months after treatment completion, deemed a critical period.

> *'it did feel like I was quite abandoned for quite like a bit, because there's quite a big gap between my last treatment and by next appointment, and there was no information given, so it was a lot of just trying to find stuff out myself……about four weeks after the treatment I received an information pack from the Macmillan Society, and that should have been given to me at my last [appointment], it was way too late by that point, I'd already done all the research online, it was a waste of time, if anything it actually just upset me more than anything else, because this could have been*

> *really helpful given a bit earlier'* (P28, T1, male, 24 yrs, In a Relationship, Chemo)

Participants reported receiving conflicting or vague information on young adult issues, regarding the use of contraception and sun cream, as well as when they could expect to resume work, socialising and drink alcohol again. A lack of preparedness could contribute to an initial sense of insecurity after treatment completion, and lowered confidence in resuming their lives. Therefore, some expressed the need for consistent and timely information on these areas to better prepare them for end of treatment, as well as signposting to support services.

> *'In terms of how it affects your sex life, for example we got a lot of conflicting information about whether we'd have, me and my girlfriend have to use condoms. There's some information, some doctors say yes you do, some doctors not so sure, we were left confused about that. Skincare as well, because there's very confusing information about whether you can go out in the sun or what you can do. Also working, I mean it's not unreasonable, I don't think, for a young adult to keep on working throughout this, and knowing what you can and cannot do is, wasn't made very clear at all'* (P28, T1, male, 24 yrs, In a Relationship, Chemo)

> '*as a younger person getting something like cancer that you never expect to get at this sort of age, it would be good to just be given all the info, as much information as possible about support organisations'* (P24, T2, female, 37 yrs, Married, Chemo)

The psychological impact of losing a sense of security after treatment completion meant an increase in fears of a recurrence, which manifested in frequent self-checking for cancer lumps. P4 described initially struggling with repeated and obsessive self-checking that contributed to escalating anxiety by Time 2.

> *'For the first couple of months, I was going to the doctor like every week, can you feel this…. I'd never like checked my boobs or anything since like I was like, it was the first time of doing it, I was like oh my god, what's that, what's that, and [doctors] were like 'it's normal it's a gland, ….because I dunno you were on your own then, apart from your check-up you are on your own, so that was the scary part about it, but yeah get on with it'* (P4, T2, female, 22 yrs, In a Relationship, Chemo)

Participants' insecurities seemed to be compounded if the disease had been present in the chest area, so had not initially experienced visible lumps or pain. Therefore, the invisibility of the disease seemed to magnify fears over a recurrence being missed.

> '*I'm now checking my neck like crazy, or even checking some moles, thinking maybe it's a bit darker, maybe it's not normal? So a bit more scared of things, because, well when my cancer came… I had no symptoms, and it didn't hurt, it started in the chest, it became quite big, it's a bulky type and I didn't feel it.. that's why you're scared, because, well just probably not being diagnosed on time, I'm*

> *just scared of that, not being diagnosed on time'* (P26, T1, female 26 yrs, In a Relationship, Chemo)

Without constant medical surveillance, participants had to adjust to the loss of medical reassurance in order to get on with life. Participants maintained the importance of self-checking and being on '*lump watch'* (P11) as well as relying on the reassurance and 'safety net' of clinical appointments. Yet participants sometimes wanted more reassurance from health professionals over bodily sensations to normalise their experiences. In fact, receiving advice from the oncologist on the nature of a potential recurrence meant that one participant (P24) stopped checking for lumps which reduced anxiety.

> *'If it was to come back, you're more body aware, so I would know the signs and symptoms to look out for'* (P27, T1, female, 37 yrs, Married, Chemo)

> *'[Oncologist] said look, if it's going to come back you'll know about it, it will present itself quite noticeably, and she said even if you found a lump or even if you didn't find it for a couple of months, she said we would still treat it in the same way, and even if you found a lump we probably wouldn't do anything about it until six weeks…to see what happened. So I think just her saying that, I've stopped feeling around, because any time I've felt around I've found something, and I've just realised it's making me more anxious, so I've not felt around at all, since she said that'* (P24, T2, female, 37 yrs, Married, Chemo)

Male participants in particular, expressed ambivalence over seeking out the support of the CNS once treatment was over, influenced by the sense that other patients were more deserving of their time and attention, the perceived busyness of staff, the desire to cope independently and of not wanting to be perceived as a *'hypochondriac'* (P11). One participant (P3) was unsure over whether he could approach the CNS for support ('*I get the feeling that [CNS] only comes to you if you ask'* P3, T1).

6.2 Letting go of fears of recurrence

Participants attempted to control their fears of recurrence through rationalising anxious thoughts, and others valued partners or friends who helped them to '*snap out of it'* (P4, T2). Some participants attempted to see their risk of recurrence as the same as the normal population, which appeared to help restore feelings of security ('*I'll just have to think I'm the same boat as everyone else in the world*' P3, T2).

> '*It has made me feel anxious, but I've just tried to talk myself down from it. And I keep telling myself... the last scan was negative, so I'm sure it's not going to come back that quickly, touch wood, so I just keep telling myself if I find any lumps I'll just ring up straight away, or if it starts to feel even stranger then I'll ring up'* (P24, T1, female, 37 yrs, Married, Chemo)

As was the case with the testicular cancer patients, most Hodgkin lymphoma participants were eventually able to manage their fears and so their psychological wellbeing was felt to be improved ('*I try to think about nice things in the future'* P4, T2). Letting go of fears was also helped by positive perceptions of the disease, such as perceiving it as a transient threat. By Time 2, these feelings of insecurity had been resolved in most participants, and were more often present in the first few months post treatment.

> '*I feel back to where I was previously, in terms of how I am just generally and mentally'* (P28, T1, male, 24 yrs, In a Relationship, Chemo)

One participant (P4) struggled to let go of fears, which had escalated after Time 1, so recovering a sense of security in her body meant seeking help from the GP in the form of anxiolytic medication, which helped her cope with fears.

> *'it's nice to be cancer-free and just try and get back to normal but it has been hard at the same time as well… I was put on anxiety tablets just for the simple fact, cos I didn't know it was there before I just started having a massive panic and started checking myself all the time .. I was really paranoid about missing something, I think it's more because I've got a baby that I panic, but yeah gave me some tablets and I was fine, it just keeps you calm … but it's hard at the same time cos your constantly in the back of your head…will it come back?'* (P4, T2, female, 22 yrs, In a Relationship, Chemo)

This was also the case in another participant, as greater uncertainty at Time 2 was influenced by having a relapse (P3) and awaiting his final 'all clear' appointment. Another participant (P22) experienced difficult emotions surrounding cancer *'anniversaries',* which was evident at Time 2. This was compounded by the timing of cancer that struck simultaneously with a close family bereavement. Therefore, by Time 2 she felt the experience had culminated in a delayed psychological impact. Adopting a strategy of emotional self-nurture replaced the initial 'getting on with it' approach in this participant, who realised her need to emotionally recover.

> '*I think, all in all… on top of the cancer and bereavement and some of the things suddenly come up and bite my backside for that, other things have happened on top of it all, so I felt sinking a bit'* (P22, T2, female, 39 yrs, Married, Chemo+R)

Others at Time 2 seemed either unchanged or had learned ways of coping with anxiety over a recurrence, which had been an initial struggle. For some this involved accepting occasional bouts of anxiety as part of life beyond cancer, which was a helpful strategy. Some participants felt they had generally relinquished these initial fears and concerns by Time 2 aside from occasional worries ('*majority of the time you know, I'm able to just look positively to the future*' P24, T2). In fact, focusing on their recovery and the positive aspects of their lives and actively choosing to avoid dwelling on the experience was an important strategy.

> *'to be honest I'm a little bit surprised I thought I might feel anxious all the time about it but actually I don't feel, it's almost a bit strange the whole fact that I was off for so long last year almost seems quite surreal now, so it's only if something triggers it…. but no I'm not aware of being anxious all the time…actually I've in a way just put it*

> *out of my mind and other things have taken over*' (P6, T2, female, 34 yrs, In a Relationship, Chemo)

6.3 Accepting a more precarious life and living more 'in the now'

The process of accepting that the future was potentially now more precarious in terms of the threat of recurrence or future secondary cancers, but choosing to make the most of life and live more 'in the now' was particularly salient for these participants.

> '*You then feel that your life is more precarious maybe in a way.. that it might come back at some point*' (P6, T2, female, 34 yrs, In a Relationship, Chemo)

Participants were determined that they wouldn't engage in thinking about '*what if's'* (P27) anymore and accept the uncertainty of the future. For some, this meant tolerating and accepting the chance of future biographical disruption to their careers or fertility for instance. In one participant (P11), the disease put career plans on hold for several years, however, he exhibited a sense of acceptance towards the disruption.

> '*I'm kind of prepared for either to deal with something serious in the future, so either this coming back or something similar or some other form of cancer, I'm very much mentally prepared for that to happen but I'm hoping if it does happen it's not gonna be for another 20 or 30 years so I can have a bit of a break [laughs]'* (P6, T2, female, 34 yrs, In a Relationship, Chemo)

Participants coped with this through choosing to make the most of ‘now’, as some felt empowered to initiate new plans and goals which would enhance their lives, often centred on the desire to make up for time lost. For other participants, this could mean a greater appreciation of their current lives and focusing on ‘*taking each day at a time’* (P4, T2) and living with greater intentionality, rather than planning for the future.

> *‘thinking of it positively, having something like cancer makes you feel quite empowered, you feel like, I’ve been through the mill, I’m not going to do a job that I don’t want to do, and it’s just made me, made me think more consciously about what I do want to do’* (P24, T2, female, 37 yrs, Married, Chemo)

Often to a greater extent than the testicular cancer sample, these participants had a particularly strong desire and urgency to bring the future forward in terms of making significant changes or planning new challenges, which would help restore and even enhance their fractured lives and identities. New challenges could involve planning to leave their current employment, starting their own business, retraining for a new career, planning sabbaticals from work or overseas trips.

> *‘it’s given me more of a boost to get on and do things and do challenges, I want to [travel], and I’d like to do that and raise some money and do a bit of sightseeing as well....normally, I would have gone oh, I’ll never do that, I’m too busy.., because before I was just being a mum and I wasn’t really taking any time for me’* (P27, T1, female, 37 yrs, Married, Chemo)

This was evident across Time 1 and 2 interviews for some participants as returning to the old normality at work could be unfulfilling.

> *'I did really want to go back to work I did miss work, but going back to work made me think that there are other things that I want to do now as well…it's got the stage where I feel as if, I think maybe after everything that's happened as well, I feel as if I either need to leave my job or I need some kind of sabbatical or some time away to do something very different for a while….'* (P6, T2, female, 34 yrs, In a Relationship, Chemo)

The desire to make the most of life and initiate new challenges was influenced by the threat of mortality as well as having a strong sense of missing out on life during treatment.

> '*you're young and you just want to run, you want to do things, it's not only about having fun, but you want to build your future and work and earn money, have a house, pass the driving test, and you think that everything's on delay, you just have to get better'* (P26, T1, female 26 yrs, In a Relationship, Chemo)

This was particularly salient in those who had advanced or relapsed disease, who exhibited a strong hope for a second chance at life in response to the threat of mortality that disrupted taken-for-granted assumptions towards their life trajectory.

> '*The reality of it when you actually think well ok I've got something and it could finish me off, yeah it smashes your life.. it just puts*

> *everything else into perspective...it's changed everything totally, you can't buy time, you can't buy your way out of cancer, but if you get a second chance and you've got the time given to you, then make the most of it'* (P3, T2, male, 35 yrs, Married, Chemo+SCT*)

These changes were also deemed necessary as a way of promoting emotional wellbeing by female participants in particular, who were motivated by the desire to take more time for self-nurture and have more '*me time'* (P22, T2). Self-nurture was achieved through going to retreats, support groups, talking to 'normal' peers and through planning holidays *('I try and take time out every day just to do 10 minutes of meditation'* P24, T2).

For some participants at Time 2, having this changed outlook on life after cancer was felt to be occasionally challenged when resuming normality. In one case (P3), a sense of urgency to make the most of life (as well as steroid induced euphoria) led to extreme spending, as he described a balancing act between these actions and realising the possibility of survival and of needing to save money for the future.

> *'It's a reality check, it's a sledgehammer on your life, someone telling you you've got something that could kill you, why waste your time saving for when you retire, when you might not even make it til your 40 ... you've got to get it in check cos there's an extremely high chance that they're gonna cure me, so I don't wanna go and spend all my money this year, and then someone tell you you're cured ... but then you don't wanna sit there and not experience things.... your*

> *bordering on don't go too mad but you want to do everything now'* (P3, T1, male, 35 yrs, Married, Chemo)

Therefore, some participants had to learn to find a middle ground between their new perspective after cancer, including their desire to live life more 'in the now' and the need to accept their real feelings towards issues encountered in daily life ('*you feel that you shouldn't feel down'* P6, T2). For example, one participant (P6) described a sense of guilt over feeling occasionally sad or annoyed over trivial events, as these emotions conflicted with her changed outlook.

> *'That kind of perspective can get lost when you get back to normal life…sometimes if you feel a bit sad about something you can then have this guilt for thinking well I shouldn't really feel sad about it, cos I shouldn't feel sad about anything I'm still alive I'm still here, so I should be grateful to be here, I haven't got the rights to feel sad about anything… like sad about not getting a promotion…. but then the thing is you can't live the rest of your life like that, you have to sort of just get on with it and say no I do deserve to have that promotion'* (P6, T2, female, 34 yrs, In a Relationship, Chemo)

One participant felt initially unmotivated to go to work, so restoring a sense of balance between this new attitude and behaviour was a challenge.

> *'I'm not really that bothered about it at the moment, I kind of think oh it's only work, whereas before work was ultra-important to me I'd be there all hours, now I wake up in the morning and I think I'm not gonna bother about going in this morning, so I've gone a little*

> *bit too way the other way now, I've got to reign in a little bit*' (P3, T1, male, 35 yrs, Married, Chemo)

6.4 Maintaining hope for parenthood

Hodgkin lymphoma survivors who were childless or wanted more children attempted to maintain hope for future parenthood and accept the need to 'wait and see' over future fertility, which helped them to adjust to the threat. Particularly for female participants who desired future children, the threat to fertility was a paramount concern. For the only single participant (P6), this meant rejecting the offer of choosing a sperm donor and freezing eggs, primarily as this would delay treatment.

> *'I thought I would take my chances with that 80% [chance of fertility being preserved] and I would leave everything and just hope that it would be ok in the future'* (P6, T1, female, 34 yrs, Divorced, Chemo)

For male participants, they saw sperm banking as a '*safety net'* (P11) and took a similar stance as the testicular cancer participants, in terms of pragmatic acceptance of the issue, yet were concerned to know if their fertility would return. Some female participants were warned to wait for two years following chemotherapy before attempting to conceive. Accepting this 'waiting game' could however be a struggle.

> *'if say hypothetically if me and my boyfriend were able to have children and everything worked out ok and the children were fine, it's gonna have less of an impact, but if because of the cancer treatment they said ok you can't have children or your children will*

> *be very deformed or won't make it even to birth… well that will have a bigger impact because that's a direct result of going through cancer and chemotherapy.. but I think at the moment it's a little bit hard to say I think it's one of those things that might have a very deep effect and come to the surface a couple of years down the line'* (P6, T2, female, 34 yrs, In a Relationship, Chemo)

In one single participant (P6), hopes for future parenthood were buoyed by having found a partner by Time 2, although being told to wait two years caused concerns over leaving it too late to conceive.

> *'They told me to wait for at least 2 years after the end of chemo before trying to have children, but, the thing is you don't know until you try… so I do worry about that… probably more than anything else actually, because I suppose it's not just with having a boyfriend as well, it's not just that I wouldn't be able to have kids but then he would be affected by not being able to have kids….and he keeps saying that he doesn't mind, but I know that he would ideally like kids and also probably quite a few, whereas I haven't really got a lot of time for that either, so there's the whole age thing as well, so… that's really preoccupying me a bit at the moment, but there's nothing that I can really do about it I suppose*' (P6, T2, female, 34 yrs, In a Relationship, Chemo)

Female participants attempted to reframe this period as a 'free window' of opportunity in which they were able to initiate plans and strive towards health goals to try and maximise their own wellbeing, and so make the most of this time. Some felt they had a set date for attempting parenthood, as the threat to fertility had increased their desire for a family.

> ‘*when those two years come I’m going to try for a baby, so it has changed the future plans, because it’s like more a set date, so I have like a period where I’ll try to get my best health, if it doesn’t come back I just want to be as healthy as possible, that’s my dream. So like exercise, be in shape… like the best me, so I’d like to achieve that’* (P26, T1, female 26 yrs, In a Relationship, Chemo)

Other female participants were given conflicting advice, and told they could start a family soon after treatment completion, while another participant was told to wait one year.

> *‘I asked [oncologist] if we did want to try for another baby, if we had to leave it for a set period of time, because looking on forums, some oncologists recommend leaving it for at least 12 months after your chemo…but the doctor that I mentioned it to at the follow-up said she hadn’t heard about leaving it for any period of time’* (P24, T2, female, 37 yrs, Married, Chemo)

Whilst one participant initially felt upset as they wanted more than two children, they decided against attempting pregnancy and appreciate the children they had already (*‘I’m blessed and thankful for what I’ve got’* P27, T1). This was also echoed by P4 who already had one child.

> *‘They’ve told me they don’t know, it’s 50:50 if I could [conceive] or couldn’t, for me personally, I’m happy with just one [child].. he was*

> *my miracle baby anyway, well personally I don't wanna have any more children… it's not a big deal, it would be a big deal if I didn't have any kids cos it would be a choice for me to make that was taken away'* (P4, T2, female, 22 yrs, In a Relationship, Chemo)

Hodgkin lymphoma survivors expressed several unmet support and information needs regarding fertility related issues, as some felt health professionals gave inadequate or vague information on fertility, particularly the process of testing fertility. Some had to take an active approach to elicit information, and so would have liked more information which was freely offered by health professionals. Female participants wanted more written information to take away and digest.

> *'I asked the consultant and he just said, just need to wait and see, and I said 'are there any tests that I can have done to find out if I am now infertile?' and he just said 'not at this stage'.. but I wasn't given any information. I would have liked to have been told well give it sort of six months, if you haven't had any periods then we would do this kind of test or refer you for this kind of test or speak to your GP, because I don't even know how I would be tested to find out if I'm still fertile, and I know it's probably too soon, but I felt like that was something that was quite badly handled….because even if we decided we didn't want any more children, just to know whether you could or not, whether you had to carry on using contraceptive, is something you need to know'* (P24, T1, female, 37 yrs, Married, Chemo)

Summary of transition 2

The aforementioned processes helped participants to restore a sense of normality in their lives. However participants encountered challenges in different areas, which were more evident in the first few months following treatment completion, often due to chemotherapy-related side effects. These survivors particularly struggled with the loss of security at treatment completion, which was influenced by a lack of support and information, particularly knowing ‘what is normal’ regarding their physical recovery and when they could resume normal activities. They also struggled to let go of fears towards a recurrence and in accepting threatened plans for parenthood.

Chapter 8: Discussion

8.1 Discussion of the theory of psychosocial adjustment to cancer

A novel theory of psychosocial adjustment to cancer was constructed for young adults, which is applicable to survivors of both testicular cancer and Hodgkin lymphoma. This theory provides an explanatory framework for how young adults can often positively adjust to the threats posed by cancer and the processes leading to a positive or negative adjustment trajectory during early survivorship. The theory centred on two key transitions (a. *gaining a sense of perspective over the threats* and b. *striving to get on with life and restore normality*) involving six key processes. These processes explain how most young adults in this study were able to regain a sense of normality and perspective, a sense of greater security in their relationships, derive positive growth, and exhibit a sense of acceptance, despite the psychosocial impact of the disease. The processes also helped to dismantle participants' initial fears over the threat to their health, future, body, relationships and identity. This theory also explains how the opposing processes to the ones stated could lead to negative adjustment as some young adults struggled to adjust to specific areas. This work builds on Brennan's (2001) social cognitive transition[3] (SCT) theory of adjustment to cancer, which conceptualises adjustment as a multifaceted, dynamic and

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[3] Brennan's (2001) theory, based on both social cognitive and coping theories, posits that cancer results in the re-adjustment of core assumptions surrounding an individuals' *life trajectory* (including goals and aspirations), *body* (appearance, fertility), *attachments* (relationships to significant others), *the self* (identity, control) and *existential beliefs* (spiritual doubt)

ongoing process, involving both positive and negative transitions and coping strategies. While the SCT model posits that cancer results in the re-adjustment of core assumptions surrounding an individuals' *life trajectory*, *body, attachments, the self* and *existential beliefs*, Brennan's (2001) theory is a generalised model of adjustment to cancer. The current theory provides a more specific and detailed account of adjustment relevant to young survivors who have a good prognostic outcome.

The interview findings offer a novel insight into the experiences of young adult cancer survivors, who have received relatively little attention in the literature to date. In particular, these findings add to the very limited qualitative research published, which has explored the experiences of survivors of Hodgkin lymphoma (Bober *et al.*, 2007; Grinyer, 2010) and testicular cancer (Brodsky, 1999; Carpentier *et al.*, 2011; Chapple and McPherson, 2004; Chapple and Ziebland, 2004; Gurevich *et al.*, 2004; Jones and Payne, 2000; Kristjanson *et al.*, 2006; Seymour-Smith, 2013). The findings from the current study illustrate that a cancer diagnosis in young adulthood is a shocking, disorientating and unexpected event, while treatment steals time from this normally industrious life stage[4] (Erikson, 1959). Following treatment completion, while there was evidence of resilience and positive adjustment in these survivors, young adults encountered challenges relating to anxiety, fatigue, fertility, appearance, work-related stress and the stigma of cancer, similar to previous work

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[4] Erikson's (1959) theory of psychosocial development has eight stages of identity development. The stage in young adulthood involves the development of meaningful relationships as a key developmental task (intimacy vs. isolation). The stage of middle adulthood involves a focus on work and family (generativity vs. stagnation).

(Bellizzi *et al.*, 2012; Kelly and Gibson, 2008; Zebrack, 2011; Zebrack and Isaacson, 2012). There was also evidence that survivors in this study who had not yet achieved key adult life-stages (Erikson, 1959), such as being in a relationship, becoming a parent or establishing a career, encountered greater threats to overcome and more unmet needs. Those who were single, unemployed and/or childless more actively strove to dismantle these issues. This finding is supported by some existing research that also shows that these demographic variables may influence distress (Smith *et al.*, 2013h; Yanez *et al.*, 2013). The processes involved in adjustment in this theory appeared to be more important than participants' treatment or disease status, which did not appear to influence survivors' perceptions of cancer as either a major or minor biographical event. This might explain the lack of substantial existing evidence regarding the role of treatment or disease-related variables in adjustment to testicular cancer or Hodgkin lymphoma (Brant *et al.*, 2011; Daniels *et al.*, 2013; Fleer *et al.*, 2006a) or to a range of cancers found in younger adult survivors (Kwak *et al.*, 2013). In this study, participants who had received more intensive treatment seemed to more actively draw upon these positive adjustment processes to dismantle the perceived threats.

The theory also explains how young adults can often positively adjust to the threats posed by cancer relatively quickly after treatment completion. This was particularly the case for testicular cancer survivors who often felt that they had returned to normality by the Time 1 interview (shortly after the end of treatment or within months of treatment completion), and rarely reported new issues of concern at Time 2, six months later. Relatively rapid positive adjustment may explain previous quantitative literature that shows minimal or no differences between normal populations and testicular cancer survivors in terms of quality of life (Bumbasirevic *et al.*, 2013; Fleer *et al.*, 2006a; Fossa, Oldenburg and Dahl, 2009; Joly *et al.*, 2002; Mykletun *et al.*, 2005; Rudberg, Nilsson and Wikblad, 2000). Some researchers have attributed this apparent lack of difference in quality of life to the lack of testicular cancer specific measures or the response shift phenomenon (Sprangers and Schwartz, 1999). Similar to the findings of Baker *et al.*, (2016), cancer survivors in this study had differing responses and meanings towards the concept of normality after cancer, either that the ‘old normality’ had resumed or they were entering a ‘new normal’. This indicates that while a response shift phenomenon may occur in some men who perceive a ‘new normal’, others feel they have returned to the ‘old normal’, both of which indicated positive adjustment.

Similar to previous research, the diagnosis of cancer was a shocking and difficult experience for the young adults in this study (Kristjanson *et al.*, 2006; Skoogh *et al.*, 2013; Trask *et al.*, 2003; Tuinman *et al.*, 2007). Following diagnosis and treatment, all participants engaged in the process of weighing up or appraising the experience. Cognitive appraisals were found elsewhere to be particularly important in explaining the variance in adjustment to cancer (Hulbert-Williams *et al.*, 2012). Male participants, particularly testicular cancer survivors, often minimised the significance of having cancer, appraising the disease as a relatively minor biographical event. Minimisation of the impact of cancer has also been shown previously in melanoma (Brown *et al.*, 2000; Winterbottom and Harcourt, 2004) and prostate cancer patients (Brunton, Booker and Molassiotis, 2012); and it has been associated with better quality of life outcomes (Brown *et al.*, 2000). Male colorectal cancer survivors were shown to be more likely than females to downplay their illness, suggesting this strategy may be particularly salient for men (McCaughan, Parahoo and Prue, 2011). In this study, the process of minimisation appeared to be an adaptive coping strategy, as it helped men defend their positive perceptions of the disease in relation to high rates of survival and reframe it as less threatening. As all had received a good prognosis, including those who had been treated for a recurrence, these perceptions likely matched the reality of participant's situation, which has been shown previously to be important in adjustment to illness (Park, Folkman and Bostrom, 2001; Sharpe and Curran, 2006).

The process of positive reframing was particularly important at helping young adults gain a sense of perspective over the threats of cancer. The concept of positive reframing, described also as positive reappraisal in previous work, has often been investigated as a static concept in cross-sectional studies examining coping strategies (Keeling, Bambrough and Simpson, 2013; Schroevers, Kraaij and Garnefski, 2011), whereas this study conceptualises positive reframing as a dynamic and multifaceted process. Positive reframing in this study was facilitated by the process of holding onto positive illness perceptions of cancer. Illness representations[5]

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[5] The main tenets of illness representations, part of Leventhal's (1984) self-regulation theory, include: *identity* of the illness (label of illness), *timeline* (duration of illness e.g. acute/chronic) *cause* (genetic, environmental), *consequences* (minor or major; physical, social or psychological), c*ontrol/cure* (perceptions over control or cure of the illness) and more recently, the dimensions of *illness coherence* (making sense of illness) and *emotional representations* of illness (fear, anxiety, sadness) have been added to the model (Moss-Morris *et al.*, 2002).

(Leventhal, Nerenz and Steele, 1984) have previously been shown to be important variables in adjustment to cancer (Moss-Morris *et al.*, 2002; Petrie and Weinman, 2012; Scharloo *et al.*, 2010; Traeger *et al.*, 2009). In this study, positive perceptions involved perceiving testicular cancer or Hodgkin lymphoma as an acute and curable illness, with minimal consequences. This explained how some participants were able to positively reframe the illness, while others continued to perceive it as a threat. Crucially in this theory, perceptions of testicular cancer or Hodgkin lymphoma as a *specific* cancer helped facilitate positive adjustment as the threat of cancer was felt to be contained. Conversely, perceiving their cancer as a *generalised disease,* whereby prior assumptions about cancer as a life threatening disease were still held, could lead to negative adjustment. Taking a generalised view of cancer increased feelings of susceptibility to having cancer again in another part of the body and meant that the threats of cancer to the future were not cognitively dismantled. These novel findings build on this existing theory of illness perceptions (Leventhal, Nerenz and Steele, 1984), and suggest that a cancer specific dimension could be added to this frequently used illness perception questionnaire (IPQ) (Moss-Morris *et al.*, 2002). These findings also add to the limited existing research on illness perceptions in younger adult cancer survivors (de Castro *et al.*, 2012) and in cancer survivors in general (Hopman and Rijken, 2015; Husson *et al.*, 2013; Keeling, Bambrough and Simpson, 2013; Traeger *et al.*, 2009).

The process of resolving the discrepancy between participants' assumptions and the actual experience of cancer helped participants form positive illness perceptions, as well as gain a sense of coherence[6] over the event (Antonovsky, 1987; Moss-Morris *et al.*, 2002). A sense of coherence has previously been shown to predict good quality of life and is inversely related to depression, so together with the current findings, this concept might be useful for identifying patients at risk of maladjustment (Allart, Soubeyran and Cousson-Gélie, 2013; Eriksson and Lindström, 2007; Pillay *et al.*, 2015; Sarenmalm *et al.*, 2013). In this study, participants who struggled to gain a sense of coherence exhibited a sense of ambivalent acceptance towards the disease, influenced by what was felt to be distorted cultural and societal connotations and stigma towards cancer. This finding demonstrates the power of participants' prior assumptions towards cancer at influencing adjustment. Prior assumptions may be partially influenced by media portrayals of cancer (Clarke and Everest, 2006), as according to Cancer Research UK (2015a) the public fears cancer more than anything else, including violent crime, debt or dementia. In order to counteract these societal views, participants in this study strongly sought to defend their positive perceptions. One previous study of testicular cancer survivors also found that cancer stigma was an issue for participants (Colbourne, 2005). The findings from the current study highlight the importance of the role of societal and cultural factors specific to cancer survivorship, which might

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[6] A *sense of coherence* is a concept frequently used to explain positive adjustment, described as a global orientation referring to an individual's perceptions regarding the *meaningfulness, comprehensibility* and *manageability* of the illness (Antonovsky, 1987). This relates to the concept of *illness coherence*, which has been incorporated into the frequently used illness perception questionnaire (IPQ) (Moss-Morris *et al.*, 2002).

threaten survivors' positive and adaptive illness perceptions, and thus threaten adjustment.

The ability to find a sense of meaningfulness from an event is also a dimension of the sense of coherence concept (Antonovsky, 1987). Participants who received more intensive treatment more actively derived and held onto a sense of positive meaning or psycho-spiritual growth from having cancer, which has been previously associated with positive adjustment or 'thriving' (Allart, Soubeyran and Cousson-Gélie, 2013; Parry and Chesler, 2005). Previous studies also indicate that failing to make sense of a traumatic event can lead to rumination and poorer adjustment, (Arpawong *et al.*, 2013; Hefferon, Grealy and Mutrie, 2009; Janoff-Bulman, 2010; Park and Folkman, 1997), which was illustrated by the negatively adjusted case example (see p. 214) in this study, who struggled to achieve positive adjustment. In most cases, however, cancer had a transformative effect on participants, who commonly reported greater closeness to their spouse or peer group, a greater appreciation of life and a more positive outlook. Similar findings have been reported previously (Brodsky, 1995; Carpentier *et al.*, 2011; Fleer *et al.*, 2004; Fleer *et al.*, 2006n; O'Dell, 2010; Park and Blank, 2012). This study also illustrates that finding positive meaning was particularly important for those who did not have the security of having achieved key life stages of adulthood (Erikson, 1959) before their cancer diagnosis.

The process of making upward, downward and parallel social comparisons also helped participants reframe the illness. Social comparisons highlighted in this study are consistent with social comparison theory[7] (Festinger, 1954) and have been previously described as a coping strategy in testicular cancer survivors (Colbourne, 2005). Social comparisons to other patients were helpful, as participants who had achieved key life stages of adulthood often felt their experience would have been worse if they were younger or childless for instance, which is also reported among penile cancer survivors (Bullen *et al.*, 2010). Downward social comparisons have also been utilised by young female survivors to help manage their concerns over fertility and protect self-esteem (Halliday, Boughton and Kerridge, 2014). In this study, downward or parallel comparisons were particularly important for dismantling current threats, while upward social comparisons helped to dismantle the perceived threats to the future, which illustrates this is an important process in adjustment. Social comparisons to others can, however, lead to negative as well as positive consequences for cancer patients, also indicated previously (Bellizzi, Blank and Oakes, 2006; McCaughan, Parahoo and Prue, 2011). In this study, this could mean that fears towards the future were heightened after meeting other patients with the same cancer who had experienced a recurrence or disease complications.

Perceived threats to the future commonly involved concerns towards fertility and plans for parenthood. The strategy of acceptance towards the need to ‘wait and see’ over future parenthood was helpful for some participants, yet could be a struggle for those who imminently wanted

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[7] Social comparison theory (Festinger, 1954) posits that individuals make downward social comparisons to other people worse off, which lead them to re-evaluate their own situation. Upward social comparisons are made to individuals perceived as better off, in terms of recovery for example, and parallel comparisons to those seen as in a similar situation.

children. Existing research shows that testicular cancer survivors who achieve parenthood are more likely to have a better quality of life than those who desire children yet are unsuccessful (Stoehr *et al.*, 2013). The current study also indicates that young adults who imminently want children after cancer might have greater supportive care needs, and that concerns and uncertainty over their ability to achieve parenthood was particularly salient for female survivors. Amongst female participants, there was variation in the information given regarding when to start attempting to conceive, with some being told to wait one year, whilst others were told two years or another participant was told not to delay pregnancy at all. This finding adds to previous research showing that fertility information is perceived by younger adults to be patchy and inadequate, including the support and information received after treatment (Absolom *et al.*, 2009; Adams, Hill and Watson, 2013; Grinyer, 2009; Shine Cancer Support, 2013; Wright *et al.*, 2014). Female survivors in this study often attempted to reframe this waiting period as a 'window of opportunity' for initiating plans or goals, which was an adaptive way of coping with this issue. Single male participants could express concerns over future relationships being affected by the threat to their fertility, although there was less evidence of this anxiety than in a previous study (Carpentier *et al.*, 2011). While existing research shows similar levels of quality of life between men who banked sperm and those who did not (Pacey *et al.*, 2013), this study indicates that sperm banking was highly important (unless men didn't want more children) in terms of helping men feel more secure in their futures. This adds to previous literature which has focused on communication around sperm banking (Chapple *et al.*, 2007; Eiser *et al.*, 2011).

Testicular cancer survivors in this study quickly accepted and normalised the loss of a testicle, exhibiting few or transient body image issues, contrary to some previous qualitative literature (Carpentier *et al.*, 2011; Gurevich *et al.*, 2004; Kristjanson *et al.*, 2006), although similar to other work (Brodsky, 1995; Chapple and McPherson, 2004). It is possible that men's lack of concern over this issue is due to the sample containing a self-selecting group of particularly well adjusted men (see Limitations section). Humour was important in coping with the loss of a testicle, shown elsewhere to be a particularly important coping strategy for male cancer survivors (Campbell-Enns and Woodgate, 2013; Chapple and Ziebland, 2004; Oliffe *et al.*, 2009). In this study, humour and camaraderie with others helped to normalise and minimise this issue, particularly within the peer group. There was also no substantial evidence that single or childless men were more distressed or had more body image issues compared to partnered men, which conflicts with previous quantitative research on testicular cancer survivors (Fleer *et al.*, 2006n; Fleer *et al.*, 2006x; Rudberg *et al.*, 2002; Skoogh *et al.*, 2011; Tuinman *et al.*, 2005; Tuinman *et al.*, 2010). However, men in this study who had not yet achieved key life stages seemed to more actively re-establish a sense of security and control through the process of constructing an enhanced sense of personhood, which helped dismantle threats to masculinity. This is supported by a previous study that demonstrates that the majority of testicular cancer survivors do not report a lasting impact on their sense of masculinity (Fosså *et al.*, 2003).

Conversely, some male participants who had received chemotherapy or high-dose steroids as part of their cancer treatment had much greater issues with visible differences to appearance, such as alopecia or weight gain. This is similar to previous studies (Brodsky, 1995; Carpentier *et al.*, 2011). Visible appearance concerns were a threat to both male and female participants' identities. Although frequently shown in female cancer survivors (Adams *et al.*, 2011), few previous studies of younger male cancer patients have highlighted appearance-related concerns (Campbell-Enns and Woodgate, 2013; Robertson, 2006; Wenger, 2013), which might now be seen as more culturally acceptable concerns for men. Hair loss was particularly distressing for females in this study, also indicated previously (Snöbohm, Friedrichsen and Heiwe, 2010; Tindle, Denver and Lilley, 2009). Distress over chemotherapy induced alopecia was, however, transient for many participants in this study. The coping strategies of taking control and acceptance were particularly important, and have also been shown in breast cancer survivors (Pilkington *et al.*, 2014). The current study also highlights novel findings regarding participants' strategies to minimise the impact of appearance changes on their children, including the use of humour, normalisation and reassurance.

In contrast to existing research (Cayless *et al.*, 2010; Wenger, 2013), in this study, biographical disruption[8] (Bury, 1982) due to cancer was relatively

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[8] Bury (1982) developed the concept of biographical disruption, which is based on the idea that illness is an event that is disruptive to self-identity, biography as well as expectations regarding life trajectory. This theory posits that individuals engage in biographical work and identity reconstruction to make sense of their illness and counter the assault to identity or 'disrupted feelings of fit' as well as taken-for-granted assumptions over their social world and body (Bury, 1982; 1997; Mathieson and Stam, 1995).

transient and did not have a long-lasting negative impact on identity in the post-treatment phase. This may be due to none or very few ongoing symptoms in participants' day-to-day lives after treatment completion, particularly evident in testicular cancer survivors. Participants' engagement in the process of preserving and enhancing the normal self helped restore the impact of biographical disruption throughout treatment and during early survivorship. This was aided primarily through striving to resume their work roles or fitness regimens as well as defend against *illness centrality* (Helgeson and Novak, 2007), as survivors in this study often rejected cancer survivorship as part of their identity. Previous studies show associations with high levels of illness centrality and poorer wellbeing (Helgeson, 2011; Park, Bharadwaj and Blank, 2011), so altogether, this highlights that maintaining a sense of normality throughout treatment and beyond is important for young adult survivors.

In this study, the majority of young adults did not exhibit substantial psychological distress after treatment. The positive adjustment processes described in this theory might, therefore, help explain the existing evidence that the psychological functioning of Hodgkin lymphoma survivors is comparable to the general population (Loge *et al.*, 1999a; Wettergren *et al.*, 2003; Wettergren *et al.*, 2004) with only a minority displaying substantial distress (Roper *et al.*, 2013), as well as literature showing that only a minority of testicular cancer survivors are affected by anxiety (Dahl *et al.*, 2005; Fosså *et al.*, 2003; Wiechno *et al.*, 2007). While up to a third of long-term testicular cancer survivors report fear of recurrence (Dahl, Mykletun and Fosså, 2005; Pedersen *et al.*, 2012; Skaali *et al.*, 2009), there was less evidence of this in this study, although some survivors reported transient concerns, particularly prior to follow-up appointments. The negative case example (see p. 214) highlights how the opposing processes to the ones presented in this theory can lead to negative adjustment. These processes explain the increase in distress and fear of recurrence by the Time 2 interview. Instead of holding onto anchors of security (relationships, parenthood status, work and confidence in their physician and CNS) and attempting to relinquish fears, negative adjustment developed from holding onto the threats of cancer and ruminating on fears. The proposed theory of negative adjustment builds on the theory of *searching for safety signals* by Jones and Payne (2000), which proposed that having fewer safety signals during treatment (hospital appointments or contact with other patients) led to poorer outcomes during follow-up for testicular cancer survivors. In their study, men on surveillance with minimal contact with health professionals and other patients, reported higher levels of anxiety than those who received treatment (Jones and Payne, 2000). In the current study, the processes of holding onto anchors of security and relinquishing the threats of cancer were more important in explaining adjustment. It might also be possible that negative adjustment reflects personality traits of neuroticism or rumination, which have previously been associated with distress (Grov *et al.*, 2009; Soo and Sherman, 2015), as well as low-optimism that has been associated with greater fear of recurrence (Crist and Grunfeld, 2013).

Participants in this study, especially females, emphasised the importance of self-care strategies and the utilisation of external resources and support in order to promote wellbeing. These included complementary therapy, relaxation techniques, counselling services, diet management, online forums and support groups. Previous research has also found that women may express more needs for psychological support compared to males (Zebrack, Mills and Weitzman, 2007). In this study, for both males and females, the process of taking an active approach helped survivors regain a sense of control over the threats and so promoted positive adjustment, which has been indicated elsewhere (Taylor, 1983). While a few men in this study recognised their need for professional psychological support or counselling, they expressed reservations over asking for or accepting such support, which reflects previous work (Kristjanson *et al.*, 2006). Previous research has also shown that while two thirds of testicular cancer survivors expressed a desire for psychological support, a later trial comparing psychological therapy versus standard care was neither effective nor well-utilised by men (Moynihan, 1987; Moynihan *et al.*, 1998; Skoogh *et al.*, 2013). In the current study, men in particular valued the informal psychological support given by nurses during treatment as well as other informal opportunities to reflect on the experience. Men also suggested that psychological support would be more easily accepted if it was offered routinely as part of the care package.

Over time, it was evident that men who increasingly adopted an active coping approach to utilising external resources and support, seemed to adjust better than those who continued being stoical or who ‘put on a brave face’ and were reluctant to reveal their hidden concerns. Previous literature has highlighted the role of hegemonic masculinity[9] for men coping with cancer (Cecil, Mc Caughan and Parahoo, 2010; Evans *et al.*, 2011; Landívar, 2005; Love, Thompson and Knapp, 2014) and has shown that cultural expectations that men should ‘be strong’ can be a barrier to support seeking (Love, Thompson and Knapp, 2014). In this study, stoicism was influenced by a more ridged adherence to hegemonic views of masculinity and the desire to project an image of an optimistic outlook. Previous work also indicates that men may endorse keeping silent over their emotional pain and put on a ‘brave face’, fearing what other men might think if they speak out (Cecil, Mc Caughan and Parahoo, 2010; O'Brien, Hart and Hunt, 2007; O'Brien, Hunt and Hart, 2005). The negative case example (see p. 214) in this study showed that prolonged stoicism over time, which concealed hidden emotional distress and concerns, led to feelings of abandonment from health professionals and a sense of isolation. Elsewhere, studies on men have shown that they are more reluctant than women to seek help for problems such as depression (McCaughan *et al.*, 2011; O'Brien, Hart and Hunt, 2007; O'Brien, Hunt and Hart, 2005). Through refusing help, men may be enacting this dominant form of hegemonic masculinity, as seeking help may be associated as a feminine health practice (Courtenay, 2000a).

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[9] Masculinity has been defined as a socially constructed phenomenon, which has multiple meanings across different cultures and historical time points (Chapple and Ziebland, 2002; Moynihan, 1998). Hegemonic masculinity is the dominant and idealised form of masculinity in a given society (Courtenay, 2000a). This is the ideal that men should behave in a way that shows they are in control, unemotional, invincible, self-reliant, and emphasises power, strength, dominance and sexual prowess (Courtenay, 2000a; Evans *et al.*, 2011). Masculinities may be influenced by age, sex, social class and race as well as sexual orientation, as subordinate masculinities might be evident in homosexual, disabled or lower class men, who may attempt to compensate for their lowered status through risky health practises (Courtenay, 2000a; Wenger and Oliffe, 2014). Courtenay’s (2000a) theory of gender and health proposes that, similar to social behaviour, health related behaviours and beliefs are “*a means of demonstrating femininities and masculinities*” for women and men (p.1385), and that greater endorsement of hegemonic ideals might be associated with riskier health behaviour in men .

The coping strategy of stoic acceptance has previously been associated with poorer adjustment (Díez, Forjaz and Landívar, 2005; Landívar, 2005). Together with findings from this study, it is evident that emotional disclosure is important for cancer survivors, especially males, who may be more likely to hide concerns. These findings further understanding of younger male cancer survivors who have been underrepresented in the literature (Campbell-Enns and Woodgate, 2013).

One of the key differences between the two samples is the greater levels of unmet information and supportive care needs reported by the Hodgkin lymphoma participants. As Hodgkin lymphoma survivors had often experienced longer and more intensive treatment regimens, these participants struggled to a greater extent with the transition from treatment to follow-up. In particular, the loss of the treatment 'safety net' led to feelings of abandonment from the health care team in some participants. This echoes the general cancer survivorship research on this transitional period (Arnold, 1999; Foster *et al.*, 2009; Jefford *et al.*, 2008; Larsson, Hedelin and Athlin, 2007; Parry *et al.*, 2011) and adds to the limited knowledge base regarding young adults' experiences of this transition (Keim-Malpass and Steeves, 2012; Shine Cancer Support, 2013; Thompson, Palmer and Dyson, 2009). The findings also suggest that Hodgkin lymphoma survivors more actively strove to regain a sense of security lost after treatment completion, particularly during the 'vulnerable window' between the end of treatment and the first few months afterwards. Hodgkin lymphoma survivors expressed the need for more age-specific information to be given just before treatment completion, including greater information on the timing of recovery, such as when they could resume working, socialising and drinking alcohol. Participants also wanted practical information on when to stop taking medication, information on sun exposure and skincare, sexual health and fertility issues, such as whether they needed to use contraception after chemotherapy and when they would be able to start trying for a family. In order to promote a better sense of preparedness for '*re-entry'*, participants' desired greater information on 'what to expect' and 'what is normal' during early recovery, as struggling with these unmet needs seemed to contribute to poorer initial adjustment, shown previously (Millar, Patterson and Desille, 2010). Some Hodgkin lymphoma survivors expressed uncertainty and confusion over how to check for lumps and the signs and symptoms of a recurrence. Participants for whom the disease had been present in the chest area (and so had not experienced the presence of lumps), seemed particularly fearful of a recurrence and exhibited a greater sense of ambivalent acceptance. Some survivors from both samples wanted more information on the duration and causes of fatigue and how to manage it, although this was more of an issue for Hodgkin lymphoma survivors. Participants attempted to manage treatment-related fatigue through maintaining aspects of their exercise routines throughout treatment, which appeared helpful for physical wellbeing, while others could struggle initially with returning to exercise regimens and lacked confidence in this area. These specific unmet needs add to the limited existing knowledge base on young adult survivors surrounding treatment completion (Fern *et al.*, 2013).

8.2 Implications for policy and practice

8.2.1 Interventions to promote self-management

The importance of developing interventions to promote self-management in cancer survivors has been highlighted previously (Fenlon and Foster, 2009). So far, very few studies have developed and tested psychosocial interventions for young adult cancer survivors (Quinn *et al.*, 2015) or specifically for survivors of testicular cancer (Martin *et al.*, 2013; Moynihan *et al.*, 1998; Pauley, Morman and Floyd, 2011) or Hodgkin lymphoma (Oldervoll *et al.*, 2003), so this study adds to this limited knowledge base. Firstly, in light of the evidence surrounding illness perceptions as potentially modifiable variables, interventions that address and even challenge negative illness perceptions may be useful for young adults, and have shown promising results in previous studies (Ashley *et al.*, 2014; Petrie *et al.*, 2002; Petrie and Weinman, 2012; Stanton *et al.*, 2013). This could be part of a psycho-educational self-management intervention facilitated by health professionals, which may be appropriate for young survivors, as found previously (Chambers *et al.*, 2012b; Chambers *et al.*, 2011; Martin *et al.*, 2013). These types of interventions can employ techniques based on cognitive behavioural therapy (CBT), which aims to challenge negative or faulty beliefs, and can be helpful in alleviating anxiety (Hofmann *et al.*, 2012). Psycho-educational interventions targeting illness perceptions could aim to help young adults struggling with fear of recurrence. It is possible that health professionals working in oncology and haematology could be trained to address patients' illness beliefs. While only some of the females in the sample had utilised professional psychological support, opportunities for those young adults who are struggling to achieve positive adjustment to access clinical psychology services as an integrated part of their cancer care, might increase the use of psycho-educational/CBT based interventions.

Furthermore, if health professionals suspect a young person is not achieving positive adjustment they might provide (or signpost patients to) psychosocial interventions that encourage the ability to let go of fears, live 'in the now', and promote active acceptance of a cancer diagnosis. This fits well with mindfulness meditation-based interventions that promote moment-to-moment awareness using self-management strategies. Mindfulness-based interventions in samples of both male and female cancer patients have shown promising results to date, such as improved quality of life and reduced psychological distress (Carlson, 2013; Carlson *et al.*, 2007; Chambers *et al.*, 2012a; Jones *et al.*, 2013; Piet, Würtzen and Zachariae, 2012; Rouleau, Garland and Carlson, 2015; Shennan, Payne and Fenlon, 2011). In addition to mindfulness, Acceptance and Commitment Therapy (ACT) interventions also aim to promote acceptance of cancer, which has shown to be a useful coping strategy in this study and in previous work (Allart, Soubeyran and Cousson-Gélie, 2013; Díez, Forjaz and Landívar, 2005; Keeling, Bambrough and Simpson, 2013; Landívar, 2005). ACT interventions have been shown to be beneficial for cancer survivors, including those with psychological difficulties (Hulbert-Williams, Storey and Wilson, 2015). It is possible that acceptance based interventions might be helpful for young adults, especially the acceptance of particularly challenging issues, such as appearance concerns and fertility. This has implications for educating nurses involved the care of young adults to be aware of the usefulness of acceptance and mindfulness based strategies, so they can educate patients on how to promote wellbeing. Where currently available in the UK, such interventions are most often provided by health and social care professionals affiliated with organisations like Macmillan Cancer Support and Maggie's Centres, such as clinical psychologists, mental health nurses, mindfulness teachers, complementary therapists or yoga instructors, rather than core members of the multi-disciplinary team.

Exercise interventions have also shown promising results in young adults (Hauken *et al.*, 2013; Hauken *et al.*, 2014) and in Hodgkin lymphoma survivors specifically (Oldervoll *et al.*, 2003). Review evidence also indicates that exercise interventions can improve the health-related quality of life of individuals with a range of cancers (Ferrer *et al.*, 2011; Mishra *et al.*, 2012). The current study suggests this may be a very acceptable and useful approach at addressing treatment-related fatigue, which was an issue for some participants. Health professionals, such as occupational therapists or physiotherapists that work in cancer care might be able to carry out such interventions with younger adults, involving education on fatigue management strategies and tailored exercise programs. This might be valuable, as younger adults in this study had unmet needs for greater information on fatigue, particularly the expected recovery time. The findings also suggest that engaging in emotional disclosure was beneficial for younger adults, so future interventions that encourage men in particular to talk about their experience and find a sense of meaning from cancer might be useful, which supports the conclusions of Fleer *et al.*, (2006n). A previous written emotional disclosure intervention in testicular cancer survivors showed promising findings (Pauley, Morman and Floyd, 2011). This strategy of emotional disclosure could be suggested by cancer nurses as a way that patients could further make sense of their experience.

The findings from this study and from previous work suggest that hegemonic masculine ideals, such as independence, stoicism and emotional concealment, which were valued by male participants to varying degrees, should be taken into account when designing interventions that are gender-appropriate (Cecil, Mc Caughan and Parahoo, 2009; Evans *et al.*, 2011). Participants in this study, particularly males, preferred to gain support in an informal way, rather than having to seek professional help, in order to maintain their desire for independence. Interventions in the form of activities that are not explicitly seen as support but which provide informal support might be valuable for younger adult cancer survivors, especially males, as has been suggested previously (Cecil, Mc Caughan and Parahoo, 2010; Love, Thompson and Knapp, 2014). The Bristol-based charity '*It's in the Bag'* runs group social events for testicular cancer survivors, such as football tournaments, which enables men to share experiences in an informal way; however is only locally available.

It has also been suggested that online or e-health interventions might minimise the stigma of help-seeking for men (Wootten *et al.*, 2015) and internet support groups were found to be a beneficial place for testicular cancer survivors to receive support surrounding decisions over whether to get a prosthesis (Bender *et al.*, 2012; Seymour-Smith, 2013). Younger adult cancer survivors have been shown to value sharing emotional and informational support with the online community (Griffiths *et al.*, 2015; Keim-Malpass *et al.*, 2013; Love *et al.*, 2012). There is also evidence that young adults in the UK are in favour of an online self-management resource that has clinical, information and social support features, as well as online contact with health professionals (Moody *et al.*, 2013). Men in this study, however, often expressed caution over unregulated online forums, although it is unclear how an online resource would be received.

8.2.1.i Peer support interventions

While a recent self-management intervention used a group workshop format, which was valued by testicular cancer survivors (Martin *et al.*, 2013); men in this study commonly rejected the idea of group support. Some female survivors were generally more positive towards the idea of a support group, and suggested the need for a younger adult specific support group. One-on-one peer support was reported by participants in this study as particularly valuable, which has been echoed elsewhere in prostate cancer survivors (King *et al.*, 2015). In particular, study participants emphasised and even preferred talking about giving informal peer support, although they did also value receiving peer support on a one-on-one basis. Some regretted the lack of a cancer ‘buddy’, which has also been reported previously (Shine Cancer Support, 2013; Tindle, Denver and Lilley, 2009). Low-cost, volunteer-led, peer support interventions have been reported as useful for people with a range of cancers (Allicock *et al.*, 2014; Galdas *et al.*, 2014; Lepore *et al.*, 2014; Meyer, Coroiu and Korner, 2015; White *et al.*, 2014) including younger adult cancer survivors (Zebrack and Isaacson, 2012). Peer support helped participants in this study engage in the processes of reframing, acceptance and normalisation towards the threats of cancer, and gave participants a vital source of social comparison and experiential information. Patient-buddy or peer support services could be facilitated by health professionals, such as nurses, or patient leaders. Currently, the Lymphoma Association offer a buddy system, so nurses or patient navigators (see below) could help signpost patients to this resource early on in the treatment phase. Some participants felt peer mentoring should be offered around the initial stage of diagnosis and beginning of treatment, while others felt that after treatment completion was more important, particularly if longer treatment was required. While this has important implications for the inclusion of mentoring in care provision, a cautionary approach may be needed as downward social comparisons to other patients could also have a negative impact, as previously discussed. The importance of matching survivors on characteristics, such as time since treatment as well as demographic and disease variables, has been shown in this study and previously suggested as an important consideration (Scott *et al.*, 2014). The current study also suggests that peer support interventions might be particularly important for those who are single and who do not have a partner to confide in. The Teen Cancer Trust (TCT) currently holds conferences ("find your sense of tumour") for 18-24 year olds in the UK, where survivors can meet those in a similar situation. Shine Cancer Support also organises residential weekends away for survivors between 20 and 49 years old. The current findings suggest that there might be acceptability issues regarding this type of peer support, especially for males, and some survivors might prefer more informal, convenient and one-on-one peer support.

8.2.1.ii Patient navigators

In this study, it is apparent that age-appropriate signposting to services may also be particularly helpful for younger adult survivors. In cases where this was received, often from the CNS, patients strongly valued signposting to support services including childcare, financial support, complementary cancer centres or counselling services. While the CNS may have multiple demands on their time, the role of a patient navigator (Freeman and Rodriguez, 2011) might be appropriate for younger adults. Although patient navigators are often available at local Macmillan or Maggie's cancer centres, none of the participants in this study had been directed to this resource. There is evidence that patient navigators may be evaluated positively by patients due to their role in providing emotional support and information, signposting to services and sources of support and at helping patients feel empowered to ask questions during clinic (Gabitova and Burke, 2014; Schlueter *et al.*, 2010). As participants often desired experiential information, patient navigators could signpost patients to well-regulated online sources, such as the 'Healthtalkonline' website, which includes videos and narrative accounts of cancer survivors (Ziebland and McPherson, 2006). Only one participant in this study had been signposted to this resource. Patient navigators might also be beneficial for socially disadvantaged groups (Fiscella *et al.*, 2012). Pilot studies of health and wellbeing clinics by Macmillan have also recommended the presence of trained cancer survivor volunteers (Macmillan Cancer Support, 2011). In fact, an evaluation of these clinics concluded that patients subsequently used less NHS resources and were more confident to self-manage after cancer (Department of Health, Macmillan Cancer Support and NHS Improvement, 2013). The use of positive upward comparisons to a support volunteer may be helpful psychologically and has been associated with lower depressive levels in women with higher threat appraisals towards cancer (Legg *et al.*, 2011). Patient navigators may, therefore, be able to provide both informational and psychosocial support to younger adults, as well as a source of peer support. Utilisation of patient navigator support services may be particularly appropriate as participants in this study preferred support that was informal and thus respected their desire for independence. Younger adults also exhibited preferences for talking to those who were of a similar age and disease type, which might need to be taken into consideration when matching patients with volunteers.

8.2.2 Public health interventions

The findings also have implications for public health interventions, in terms of reducing public stigma and fear of cancer, through promoting more positive messages about cancer survival, particularly for testicular cancer and Hodgkin lymphoma. It is possible that this sort of intervention could reduce delays in presentation resulting from a fear of a cancer diagnosis. Current survival statistics are often based on ten year survival estimates, such as the Cancer Research UK statistic that 50% of cancer patients will survive for at least 10 years (Cancer Research UK, 2015a). As younger adults could be typically living for another 40 to 50 years, finding ways of promoting awareness of cancer survival in a way that doesn't alarm young people is needed. For men with testicular cancer in particular, promoting positive messages of survivorship, such as men's quick and positive adjustment to body image found in this study, might also encourage earlier presentation. The finding that some men concealed their distress has implications for future public health interventions that could educate boys on the importance of emotional disclosure and could normalise help-seeking behaviour for psychological issues. This is important in light of the reported higher suicide rates in testicular cancer survivors (Alanee and Russo, 2012; Beard *et al.*, 2013) and younger male cancer survivors in general (Lu *et al.*, 2013).

8.2.3 Age and gender appropriate information and support

The findings highlight important areas where health professionals might increase their effectiveness in providing cancer patient information, facilitate cancer patient education, and improve the provision of support for this patient population. Firstly, more timely and age-appropriate information, education and support might be required at treatment completion, as Hodgkin lymphoma patients in particular, felt this was lacking (see p. 297). Greater patient education is important as the NCSI advocates that "*information and education for patients is crucial to sustaining recovery*" (p.73) indicating the importance of educational interventions (Department of Health, Macmillan Cancer Support and NHS

Improvement, 2013). The NCSI also recommends that survivors should all be offered a recovery package, including a treatment summary, care plan, an education and support event, as well as a HNA (Department of Health, Macmillan Cancer Support and NHS Improvement, 2013). This does not appear to be happening uniformly for Hodgkin lymphoma patients, also reported in cancer survivors elsewhere (Keesing, McNamara and Rosenwax, 2014), but would appear to be welcomed by younger adults in this study. Recovery events recommended by the NCSI may include education on cancer site-specific issues, information on financial or return to work issues, as well as potential signs and symptoms of a recurrence (Department of Health, Macmillan Cancer Support and NHS Improvement, 2013). This might be particularly useful for younger adults with Hodgkin lymphoma especially if this included age-appropriate information. The Maggie's cancer centre '*where now*?' course or the Penny Brohn cancer centre '*living well with the impact of cancer*' (Polley *et al.*, 2013) have also been recently developed and may be useful places to signpost younger patients to, although these services are not universally accessible (Department of Health, Macmillan Cancer Support and NHS Improvement, 2013). Community-based support programs such as these might help address psychosocial concerns and relieve pressure on NHS services.

Findings also suggest that men in particular might need prompting in order to encourage them to discuss their concerns, particularly fear of recurrence, fatigue, testosterone levels, or reasons for feeling in a low mood. Identifying such concerns will enable health professionals to assess if additional psychological support or information is needed, or whether additional support services would be beneficial for that individual. A testicular cancer or Hodgkin lymphoma specific patient concerns inventory (PCI) could act as a tool to facilitate discussions (Rogers, El-Sheikha and Lowe, 2008), but requires development. The HNA is recommended by the NCSI to assess the needs of all adults with cancer before and at the end of their treatment to support transitions to survivorship (Department of Health, Macmillan Cancer Support and NHS Improvement, 2010; Young *et al.*, 2012). The findings from this study illustrate that tools such as these might be particularly useful for younger adults, especially males. However, previous work has highlighted barriers to implementing the HNA or PCI by health professionals and variations in use of these tools (Wells, Semple and Lane, 2015).

The current study also highlights the need for health professionals, especially nurses, to be aware of and help participants to accept permanent body image changes or find ways of coping with temporary visible changes, such as alopecia. An outdoor activity intervention for younger adult survivors was shown to have beneficial effects on body image (Rosenberg *et al.*, 2014). Participants in the current study were enthusiastic about resuming their fitness routines, so interventions which combine peer support and exercise may be appropriate. As social support and being part of a strong social network were particularly valued in this study, and found previously to be associated with better adjustment (Allart, Soubeyran and Cousson-Gélie, 2013; Soares *et al.*, 2013), health professionals could assess patients' social resources so that those without supportive networks are offered additional support. In this study, patients also valued having positive illness perceptions towards their cancer shaped by information from health professionals, suggesting that this might be an important part of discussions with patients along the illness journey. This contrasts with some previous research conducted with thyroid cancer patients who felt that the label of having a ‘good cancer’ meant they received limited support from health professionals, although the authors recommended that language, such as ‘treatable’ may be more beneficial (Easley, Miedema and Robinson, 2013; Ridgway *et al.*, 2014). While some participants in this study valued being told they had a ‘good’ cancer or ‘the best one to get’, those more negatively adjusted found this language undermining by health professionals, similar to the aforementioned studies.

The variations in advice given by health professionals on when to attempt parenthood have implications for the standardisation of guidelines on this issue and in the information given to younger adults. Currently, the Lymphoma Association (2013) guidance states that a two year period of waiting after treatment is recommended, yet acknowledge that advice may vary depending on the views of the health care team. Delaying pregnancy may be required due to the higher chance of a recurrence during this period (Lymphoma Association, 2013). There is, therefore, a need for further consensus amongst health professionals. Younger adults who want children imminently might need ongoing support from their oncology team. Survivors in this study also suggested that more written information on fertility would be helpful, as well as the offer of a referral to psychological support services. Hodgkin lymphoma survivors whose disease was not palpable (or had been present in the chest area) were particularly fearful of a recurrence, which has implications for improving the education patients receive from health professionals about checking for recurrences in order to promote self-efficacy to monitor their body.

8.2.4 Follow-up design

The study findings highlight some of the limitations of current follow-up care in terms of support with the psychosocial aspects of cancer in young adults, as follow-up currently tends to focus on the detection of recurrences (Lewis *et al.*, 2009). Addressing these wider psychosocial needs and promoting self-management might potentially reduce distress (Zebrack *et al.*, 2014d). The findings also have implications for dedicated age specific cancer services in the UK. Currently, specific services for younger people with cancer only include patients up to age 24 years. However, some patients in the present study felt caught between this group and older adults, similar to previous research (Parry *et al.*, 2011; Shine Cancer Support, 2013). Age-specific service provision and care has been shown to be important to younger adults in previous research (Gupta *et al.*, 2013; Miedema, Easley and Robinson, 2013; Millar, Patterson and Desille, 2010; Tsangaris *et al.*, 2014; Zebrack, Mills and Weitzman, 2007).

Due to high levels of positive adjustment, many participants with testicular cancer felt that attending follow-up appointments became rather pointless, especially if they simply received test results with no additional discussion. Attending follow-up could also disrupt men's sense of normality and work schedules, as well as raise anxiety levels, albeit temporarily in some participants. The findings, therefore, have implications for the way that testicular cancer survivors are followed up in the future. Due to limited funds in the NHS and the growing number of cancer survivors, the current consultant-led model of follow-up is unsustainable (Davies and Batehup, 2011). The NCSI has recommended the need for a fundamental shift in moving towards more tailored follow-up regimens, stratifying patients according to their risk, as some patients might not require extended follow-up with a consultant (Department of Health, Macmillan Cancer Support and NHS Improvement, 2013). In low to medium risk patients, the NCSI proposes that patients could have regular remote monitoring. The current findings suggest that men may be potentially amenable to remote follow-up, particularly those who are positively adjusted with few issues. Some indicated that they would be happy with telephone follow-up calls. Elsewhere, a small longitudinal survey comparing usual outpatient follow-up care with patient triggered follow-up care has been recently undertaken, although the full findings are not yet published (Batehup, 2012; Batehup *et al.*, 2014). Patient triggered follow-up involved the use of remote monitoring, a clear contact point for patients with concerns (such as the CNS), patient preparation (tailored information, self-management information event) and rapid and easy access back to the hospital pathway (without having to go through the GP) (Batehup, 2012). Preliminary results indicate that there are no differences between follow-up groups in terms of unmet needs, use of health care services or health related outcomes (Batehup *et al.*, 2014).

For patients with Hodgkin lymphoma, there are no standardised guidelines on follow-up with much variation across care units (Follows *et al.*, 2014).

Some participants suggested the need for more telephone follow-up calls by the CNS to offer support, due to the time lapse between treatment completion and the first follow-up consultation, which was often several months. The role of the CNS has been highlighted as important during follow-up, and was deemed to be particularly important by survivors in this study (Davies and Batehup, 2011). Female survivors in particular described the value of female nursing support, especially regarding support for appearance and fertility concerns, indicating their importance in providing survivorship care. One recent evaluation of a nurse led lymphoma clinic that aimed to provide holistic care showed that patients were just as satisfied, if not more so, than those receiving usual care (John and Armes, 2013). However, time constraints of CNSs and funding deficits in the NHS might mean that psychosocial support and information to patients might need to be shared amongst the wider health care team, including the patient's GP, who could also offer support and information on self-management. The findings also highlight the need for cancer nurses to be trained on the specific issues relating to younger adult cancer survivorship in order to fully meet the psychosocial needs of patients. Overall, key areas of psychosocial care, which could be further addressed by multidisciplinary health professionals, are highlighted (Table 6).

Table 6: Summary of ways multidisciplinary health professionals could promote positive adjustment

Education and information

- Discuss illness beliefs, highlighting curability, the acute and specific nature of the cancer, enabling assessment of negative beliefs and fears of recurrence
- Provide education to instil confidence to check for recurrences
- Provide education about mindfulness (or referral to appropriately trained professional) and other activities such as exercise goal setting (both during and at the end of treatment)
- Provide information about long-term side effects and discuss intervention and management options
- Provide fertility advice, including standardised advice on the timing of parenthood after treatment
- Provide information on topics including contraception, financial advice, alcohol consumption, skin care and exercise programmes (both before treatment and near the end of treatment)

Support and signposting

- Signpost patients to supportive services/charities, childcare, psychological support, nutritional or complementary cancer services
- Seek to build relationships that foster patient disclosure and informal psychological support
- Support patients to adapt and adjust to changes in their body image
- Offer post-treatment telephone follow-up and provide follow-up assessment, information and support by telephone for patients who wish to receive it
- Assess patients social resources and support networks using tools such as the HNA and facilitate age-, gender- and diagnosis appropriate patient support mechanisms, such as peer support/buddy systems

8.3 Limitations of the study

There are several limitations of this study. Firstly, the 33% response rate indicates the potential for selection bias, as these patients may not be representative of all patients seen in the clinics. It is possible that those who responded might have been more or less positively adjusted and more or less distressed than non-responders. Patients who were particularly distressed might have been more reluctant to take part and talk about their experiences and hence those responses would be under-represented in the findings. While the sample did include some patients who were struggling (either currently or previously), no patients were displaying severe emotional distress at the time of the interview. It would have been useful to sample more patients who were exhibiting more psychological distress or negative adjustment, in order to deductively test the emerging theory and extend theoretical categories. However this was considered impractical as there were a very limited number of eligible patients and recruitment was slow. The response rate was calculated on the basis of the number of returned questionnaires compared to the numbers the health professionals reported they had given out to patients. Health professionals reported that only four patients refused to take an information pack (5%), although it is possible that more patients refused and this was not recorded.

There are several possible explanations for the slower recruitment than anticipated. Firstly, upon initial consultation, health professionals seemed to overestimate the numbers of patients eligible who would be coming through their clinic during the time frame of the study and gave overly optimistic views of the response rate of their patients. It is possible that uptake might have been higher if initial non-responders were followed-up, as the study involved only a single invitation. While the ethical application stated that nurses could telephone the patient if they had not responded after several weeks, health professionals were reluctant to do this as they felt this would be coercive as well as time-consuming. As the research team were not able to access data on non-responders, no follow-up letters could be sent out from the research team. There was also no opportunity to meet participants before the interview as the information packs were given out during clinic by health professionals. This might have been helpful to establish a rapport with participants prior to the interview, which could have increased the response rate. It is also unknown whether health professionals avoided asking some patients if they perceived them to be too distressed or unlikely to take part for whatever reason.

It is likely that data saturation was achieved for the testicular cancer sample; however, time restraints of the study and slower recruitment rates meant it is unlikely that data saturation was reached for the Hodgkin lymphoma sample. However, Dey (1999) argued that the concept of data saturation is inappropriate and that data collection should continue until *data sufficiency* is reached. This was echoed by Corbin and Strauss (2008) who argued that data saturation could, in theory, continue forever, so data collection should cease when the analysis has been sufficiently well developed. In this study, sufficient data (Dey, 1999) was collected from the whole sample (n=28) comprised of two patient groups, which enabled development of the theory of positive adjustment. There is no universal consensus on a definitive figure of how many participants are enough (Baker and Edwards, 2012). The sample size in this study is marginally lower than mean numbers of participants recruited in previous grounded theory doctoral research projects (n=32) (Mason, 2010). However, Morse (2000) has suggested that grounded theory studies should contain between 20 and 30 participants, depending on the quality of the data, which was rich and in-depth in this study.

The study focused on two cancers that both have a good prognosis (Cancer Research UK, 2014p; Cancer Research UK, 2014w), so the findings may not be transferable to young adults who have survived cancers with a much poorer prognosis or those with advanced cancer. While the study did not aim to generalise, the lack of diversity of the sample characteristics is another limitation. In the Hodgkin lymphoma sample, the majority of participants (n=9) were partnered at Time 1, and no participants were single at Time 2, so there was little data regarding the experiences of single survivors. The majority of participants were also White British, although this may reflect the characteristics of the area in which participants were recruited, which has limited ethnic diversity. Although sexual orientation wasn't included on the demographic questionnaire, all participants discussed being in heterosexual relationships or desiring relationships with the opposite sex. However, it is important to note that the sample included a range of participants from different socio-economic status groups, including those from lower income and educational status groups, particularly in the testicular cancer sample.

A limitation of the face-to-face interview method employed is that during interviews, sensitive topics such as sexual relationships or late effects were seldom discussed (see reflections section for further discussion).

8.4 Implications for future research

8.4.1 Future research studies

Further research is needed in several key areas. Firstly, further qualitative studies exploring the concept of positive adjustment to cancer are needed in samples of older cancer patients and younger adults with a less favourable prognosis. Further research exploring the psychosocial impact of cancer in young adulthood on partners' and families' would also be useful, particularly in female partners who were deemed to be more distressed by the experience by male survivors. Due to the small numbers of participants, further research is warranted on younger adult survivors who experience a recurrence, as well as younger adult cancer survivors from the LGBTQI[10] community who might have specific needs and experiences. Further studies to explore the experiences and needs of single young adult survivors, particularly Hodgkin lymphoma survivors, would be useful as most participants in this study were in a relationship. Further investigation of illness perceptions in younger adult cancer survivors is also warranted, especially whether the theory of illness representations (Leventhal, Nerenz and Steele, 1984) could be expanded to incorporate a *cancer specificity* or *distinctiveness* dimension (vs. *generalised* perceptions).

These findings lay the foundations for future quantitative studies to further test out the theory and explore whether the processes can predict adjustment over time. Larger-scale studies could explore adjustment in larger samples

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[10] Lesbian, Gay, Bisexual, Transgender, Queer, Questioning or Inter-sex (LGBTQI)

of younger adult survivors and examine which sub-groups are most vulnerable. This research suggests that future studies need to consider psychosocial variables when exploring adjustment, as few studies have done this in relation to these cancers (Allart, Soubeyran and Cousson-Gélie, 2013; Grov *et al.*, 2009; Rutskij *et al.*, 2010; Soares *et al.*, 2013; Wettergren *et al.*, 2004). Further utilisation of recently developed young adult or site specific quality of life measures may be more useful in future quantitative studies (Holzner *et al.*, 2013; Hoyt *et al.*, 2013) and a recent review identified the need for further testing and development of measures that fully capture younger adults' concerns and experiences (Wakefield *et al.*, 2013).

8.4.2 Future research regarding intervention development and service provision

Further evidence is also needed regarding interventions that can enhance self-management, psychological 'thriving' and health-related quality of life in younger adults. In times of financial constraints in the NHS, there is a need for well-conducted studies to determine which interventions are both effective and cost-effective. In particular, there is a need for further investigation into the feasibility and acceptability of a one-to-one peer support or mentoring intervention for younger cancer survivors, and whether this could be part of routine care. More investigation is warranted on whether patient navigators are helpful for younger adults with these cancers, as the majority of previous studies are on breast cancer survivors (Gabitova and Burke, 2014; Schlueter *et al.*, 2010). Further studies exploring the acceptability and effectiveness of psycho-educational, mindfulness or acceptance based interventions in younger adults would also be useful. Investigation of e-health interventions for younger adult survivors is also warranted, particularly whether this could deliver online peer support as well as access to information from health professionals.

The findings add to the evidence that some patients, especially testicular cancer patients, may find alternative models of follow-up acceptable, such as remote monitoring. Further larger scale work is, therefore, needed to explore the acceptability and effectiveness of different models of follow-up for testicular cancer survivors that support men's psychosocial needs and do not compromise on the medical side of care, which could inform 'best practice' (Batehup *et al.*, 2012; Department of Health, Macmillan Cancer Support and NHS Improvement, 2013). Future research could, therefore, explore participants' experiences of follow-up and how this relates to psychological wellbeing and fear of recurrence. More research is also warranted into the development of individually tailored information, which is composed of cancer patient information that meets nationally recognised standards on a range of topics highlighted by younger adults in this study. Research is also required to test the effectiveness of PCI assessment tools in younger adults with cancer. Studies could further explore interactions between nurses and patients during follow-up clinic, and examine the benefits and challenges of providing holistic support to patients.

8.5 Reflections

Throughout the study, I have used a research diary to write down detailed notes and memos on the interviews and analysis process and reflect on my role as a researcher in constructing the data.

8.5.1 Reflections on the interview process

8.5.1.i Enhancing qualitative interviewing skills and emotional resilience

While the quality of the research interview is influenced by the participant's ability in being able to coherently and insightfully 'tell their story', the skill of the interviewer also plays a key role (Kvale and Brinkmann, 2009). The research interviewer should be skilled at listening, managing silences, remaining professional, and be non-judgemental and empathetic (Adams, 2010; Braun and Clarke, 2013). However, active listening skills can take time and practise to develop (Long, 1990); so in order to improve these skills, I undertook a 10 week 'introduction to listening' course run by a counselling charity. This built on listening skills, including the use of non-verbal body language and reflection, as well as listening to non-verbal cues such as silences, speech patterns and vocal tone (Ellin, 1994; Legard, Keegan and Ward, 2003; Long, 1990). These skills were used during interviews to encourage participants to expand upon answers, and to show acceptance and understanding. Before commencing interviews, I also volunteered in two Maggie's cancer centres, which involved welcoming and interacting with cancer patients and their families. The purpose of this voluntary work was to gain experience of talking to cancer patients and their families in an informal setting. I also undertook some observation at a local haematology outpatient clinic for half a day, observing patients being given a diagnosis of lymphoma or receiving news of follow-up results. This gave me a brief initial insight into patients' experiences of clinical appointments, receiving 'good' or 'bad' news, as well as doctor-patient conversations. Undertaking training courses and volunteer work seemed to improve the quality of the interviews over time, as well as my listening skills and ability to deal with emotive and sensitive topics. The importance of self-care strategies for the researcher when undertaking interviews on emotive topics has been emphasised previously, in terms of strategies to cope with the emotional impact of research (Calman, Brunton and Molassiotis, 2013). Strategies such as reflective writing, peer debriefing and maintaining balance through stress management techniques were employed in this study, such as meditation and exercise (Rager, 2005). While some of the issues discussed, such as fears over fertility, were upsetting, I learned to offload these concerns onto trusted colleagues. Therefore in most cases, the interviews were not particularly emotionally difficult to cope with and I found interviewing young adults a rewarding experience.

8.5.1.ii Focusing on psychosocial adjustment

Before conducting interviews, I assumed that I would find substantial evidence of distress and unmet needs in the young adult cancer survivors. These assumptions were based on previous literature that shows that younger adults are a particularly distressed and vulnerable population, as well as my own preconceptions towards young adult cancer survivorship. Once I had started interviewing participants, I was struck by how overwhelmingly positive participants were, as testicular cancer patients often perceived the experience as a minor event, and the Hodgkin lymphoma sample displayed substantial resilience, despite many having a diagnosis in the midst of important life events (after the birth of a first child for instance). I had expected to find more emotional issues, fears and unmet needs, yet only once did a participant become emotionally distressed (a female patient with Hodgkin Lymphoma), who became tearful after talking about all the support she had received from her peer group. However she quickly recovered and was happy to continue the interview. I was surprised at how survivors derived such a wealth of positive outcomes and meaning from the event, especially as some said that they felt their life was better after having cancer and felt there had been no negative outcomes. The more participants I interviewed, the more I realised that it was important to use this data to develop a model of positive adjustment, in order to show the processes involved in explaining how these younger adults were coping and adjusting well to cancer. As part of the grounded theory methodology, the use of constant comparisons illuminated how these participants differed from those who were struggling to adjust, which further refined the theory.

8.5.1.iii Interviewing male participants as a female researcher

As a female researcher interviewing a predominately male sample, I was aware of the role of gender when conducting the interviews as well as when interpreting the data. I had initial worries over whether men would disclose their issues and concerns to a female researcher on such a sensitive topic; however I found that almost all of the male participants were open, honest and willing to talk about their experience, similar to the female participants. Only a couple of men did not have as much to say, although I felt this was possibly due to their more introverted personalities. Establishing a good rapport with men before the interview certainly helped them to open up to me. In some cases, men admitted that they had told me things they had not told anyone before and even that I was the sole recipient in hearing the full story of their cancer experience. One male patient with Hodgkin lymphoma said the interviews were the only time he had spoken about the whole experience with anyone, apart from a person he went to see for complementary therapy, and that he had told me more than he disclosed to his wife. Men in particular seemed to value the opportunity to talk about their experience during the research interview, and in some cases, the research interviews seemed to have the effect of a psychosocial intervention. Participants commented that they found the interviews a useful way of facilitating self-reflection on the experience, which seemed therapeutic for them. Some said that my questions enabled them to think and to 'make sense' of the experience, and so they were able to more coherently identify more positive outcomes from the experience. This would be in line with previous research demonstrating the potential for therapeutic benefit of the research interview (Colbourne and Sque, 2005).

I was initially sceptical that some men were deliberately playing down their feelings towards the experience, and enacting out hegemonic masculine ideals. I was careful to reflect on this after the interviews and during data analysis, in terms of looking for patterns of contradiction in men's accounts. However, men were adamant that their perceptions of cancer as a minor event was genuine and they were not enacting hegemonic masculine ideals. They often discussed how the research interview provided a place where they could express their true feelings of this nature, and that this was difficult to express with others, especially spouses who they felt perceived the event as much more distressing and significant. This was confirmed at Time 2 as their views were often unchanged, and in a couple of cases, men's partners briefly came to talk to me after the interview and confirmed that the men were coping well. However I felt that men's adherence to traditional masculine values did impact on how they talked about their illness experience. During the latter part of the interview process, reading other research on masculinities and cancer helped further my understanding of the differences between men and women's responses, the ways that cancer is discussed by men and why some men adjusted poorly (Evans *et al.*, 2011; Wenger, 2013; Wenger and Oliffe, 2014). For example, during interviews, men often expressed reluctance to seek help for any ongoing physical or psychological issues. Men who felt that formal psychological support would have helped them were very reluctant to utilise this support, which seemed to be strongly influenced by their adherence to traditional masculine values. As a researcher wanting to find ways of addressing unmet needs through interventions to help men, this was initially frustrating. However, I sought to explore in-depth how men utilised their support networks and resources, particularly their use and desire for peer support or support that was informal.

Overall, I felt that because of my gender, men were willing to open up to me and help with the research project and valued being given the time and space to disclose things that they couldn't say elsewhere. They also seemed pleased that they had taken part and hoped that their accounts would help other men in the future. Some also strongly felt that talking about cancer was a way that they could enact masculine values, through informing other men of the condition and sharing 'expert' knowledge. I felt that the interview process was particularly helpful for men who were struggling, single, lived alone or facing particular issues, such as IVF. When interviewing male participants, I also felt it was particularly important to put in place listening skills and techniques, such as paraphrasing and reflection, and using prompts from the interview schedule. This was important as topics such as body image and psychological health were not readily discussed in some instances, so I felt it was important that I ask specific questions about these topics in order to explore men's views. For this predominately male sample, it is unlikely that an unstructured interview schedule would have worked as well. In some cases, I felt that men were attempting to portray themselves as strong and stoical, particularly regarding discussions of emotional vulnerability, so the use of prompts was essential, and sometimes led to men admitting to areas where they had struggled. At Time 2, I felt that men trusted me more, even greeting me as a friend, although in one case I had a friendly offer of dinner which I had to politely decline.

8.5.1.iv Discussing sensitive topics

One of the issues I found difficult to raise was the topic of sexual function, with both male and female participants. I decided not to ask participants directly about this issue, due to the sensitive nature of the topic and potential for embarrassment of the participants and myself. I also felt that as a female interviewer with no clinical background, I would be uncomfortable directly asking participants about their sexual functioning, particularly as interviews were mostly in participants' homes and with male participants. I did specifically ask participants about the sensitive topic of fertility as well as fears for the future, which again, was not something which was often raised voluntarily. Only a few participants mentioned the topic of sexuality spontaneously, (a few men with testicular cancer), although it was always in the context of stating that this area had not been affected, and that they could still function the same as before cancer. It may be possible that this issue was not a problem for most participants, rather than they were embarrassed to discuss it. The prevalence of sexual dysfunction in testicular cancer survivors has varied across studies, with a systematic review highlighting contradictory findings shown in this area (Jonker-Pool *et al.*, 2001). In this study, participants often felt that going through the experience of cancer with their partner had strengthened the relationship, although it was unclear whether this also related to their sexual relationship as well. Although possible, it is unlikely that inclusion of this topic would have altered the main conceptual processes in the theory. Another topic, which was not raised by participants, was their perceptions about the late effects of cancer treatment, which is a particularly salient issue for Hodgkin lymphoma survivors (Bober *et al.*, 2007; Townsend and Linch, 2012). While previous qualitative literature has explored this topic, I also felt unable to ask participants about this in a sensitive way, and I was unsure what they had been told and did not want to alarm them.

Exploring the particularly sensitive topics of late effects and sexual function were not specific aims of the study, so different methods may be needed to explore these topics in future studies. Methods that allow for greater anonymity, including telephone interviews, online blogs or questionnaires might have been a better way of eliciting information on these topics. Interviews conducted on 'neutral' territory by a trained clinical professional in which participants are pre-warned about having to discuss these issues, might also be appropriate. Future studies could address this by asking participants after the interview to complete an open-response 'comments box' questionnaire. This could ask participants to write about anything that they felt unable to talk about during the interview.

8.5.1.v Power dynamics

The sample included more participants from lower-socio economic backgrounds than I expected, with many on lower incomes or without many qualifications. As a relatively middle class, White British PhD student, I found that I was sometimes aware of social class differences with participants from these groups. However, I actively tried to minimise any differences or power dynamics during interviews by wearing more informal clothes and making sure that I talked about the project as a research study and tried to avoid using 'PhD' (unless participants specifically asked). I also attempted to establish a good rapport before the interview commenced through pre interview ‘chit chat’. I assumed the role of a ‘naïve’ researcher, so I felt that, overall, any differences regarding social class often did not matter and participants were happy to talk to me. In fact, we often talked for a while after the interview had finished.

Due to participants’ preferences, some interviews were conducted in a public café with background noise and other people close by. However participants generally seemed unperturbed by this and these interviews appeared in no way different to those conducted in participants’ homes. Only one interview which was conducted in a participant’s workplace felt stilted at times, as we were in an office with a glass door with his colleagues able to see in, which may have constricted his responses a little. On several occasions, participants’ young children or pets were present during interviews, or participants’ family members were in nearby rooms. Despite these occasional interruptions, participants were keen to share their stories and carry on with the interview.

8.5.2 Reflections on the methodology and design

8.5.2.i Using a longitudinal design

The design of the study involved conducting two interviews over time. I had originally anticipated that there may be many changes in participants’ accounts over time, such as an increase in fear of recurrence or distress. This view was also influenced by a clinician involved in the study who felt that his patients with testicular cancer underwent a delayed psychological reaction in the year following treatment completion. However I found that participants did not have many new things to report, so the Time 2 interview yielded little new information as participants had continued on a positive trajectory. In those who showed little evidence of change, Time 2 interviews provided further depth to the Time 1 interview data and added a richer insight, as participants often went into more detail at Time 2 about their experiences. Time 2 interviews also seemed more focused; although this could also have been influenced by a possible improvement in my interviewing skills as well as having more focused questions at Time 2. A longitudinal design also enabled participants to have time to reflect on their experiences by Time 2, and they may have anticipated the questions based on their experience of being interviewed at Time 1. Although the six month gap between interviews, partly influenced by the time constraints of the project, did not capture much change, it is unlikely that a slightly longer time interval between interviews would have significantly altered the findings, in light of the positive adjustment trajectory observed. However, a more extended longitudinal design involving a series of interviews over several years could potentially enhance and build on the grounded theory. The use of telephone follow-up interviews might have reduced the time burden of travelling to interviews; however this method may not have had the same level of rapport compared to a face-to-face meeting.

The longitudinal design also meant that I was also able to look at change over time in some participants and explore contextual influences, which was useful at helping me develop and refine the theory. However, contextual factors could influence participants' responses during interviews and added a layer of complexity when interpreting the data. Some interviews were conducted when participants had other stressful events in their lives (e.g. bereavement or job stress), which meant it was sometimes difficult to unravel what issues were due to the cancer or something else entirely. Before the Time 2 interview, one participant had just received news that he needed to have further treatment, so his responses are likely to have been different if he had been interviewed before this bad news.

8.5.2.ii Using grounded theory

Overall, I found grounded theory to be a very useful research methodology, which was appropriate for the aims of this study. During coding, the use of 'gerunds' and constant comparison were particularly helpful at enabling exploration of the processes involved in adjustment. Delaying a complete literature review regarding the psychosocial literature seemed to help the development of the analysis. I felt a complete knowledge of the literature might not have allowed novel themes to be elicited or I might have developed too many preconceived ideas regarding common themes. I was aware of the potential for imposing my knowledge of existing theories onto the data, influenced by my academic background in health psychology. However, I tried to avoid reading about theoretical ideas during the analysis process (especially during the beginning stages), until the theory had developed; however I acknowledge that the concepts in the theory may partly reflect my academic background. Later on in the analysis process, comparisons were made between the developing theory and existing theories and concepts in the literature, such as illness perceptions, social comparisons and sense of coherence (Antonovsky, 1987; Festinger, 1954;

Leventhal, Nerenz and Steele, 1984). Existing theories were a useful source of comparison and this part of the analysis indicated where concepts emerging from the data were not novel. This helped further refine the theory, and having two participant groups was also beneficial in this process of constant comparison. Later reading of the literature also helped to challenge ideas and also compare the commonalities and differences between the data and existing research.

8.5.2.iii Future methods of conducting research with younger adults

Future studies could employ methods which might be more accessible to young adults, such as recruitment via social media, which might access a wider number of potential participants, although will come with several challenges (Casanas i Comabella and Wanat, 2015). Another potential method that has been recently used in the delivery of psychological therapy to young adults is the use of Skype$^{\text{TM}}$, an internet video based communication tool (Sansom-Daly *et al.*, 2012). This has also been discussed as a useful tool for research interviews, and might allow access to a global participant population (Deakin and Wakefield, 2013; Hanna, 2012). For this study, the use of online interviewing might have meant that more participants could have been accessed, yet it would have been more difficult to access patients as they were finishing treatment. It is possible that is might be harder to establish a good rapport with the participant over Skype$^{\text{TM}}$ compared to a face-to-face meeting. All of these methods, however, warrant further investigation.

8.6 Dissemination

The findings from the interviews with testicular cancer survivors have been disseminated into a journal publication (Matheson *et al.*, 2016) (see Appendix 12). The interviews with Hodgkin lymphoma survivors have also been written into a journal publication which is currently in preparation. A third journal article is also currently in preparation regarding the views of men with testicular cancer towards their follow-up care. A lay summary of the findings has been sent to all of the participants, and the findings will be fed back to health professionals working in oncology who were involved in recruitment. The study has been presented in poster and oral presentations at several national and international psycho-oncology and psychology conferences.

8.7 Conclusions

This thesis has important findings that add to the relatively small existing body of literature on the psychosocial impact of Hodgkin lymphoma and testicular cancer in younger adults. The findings showed that cancer in young adulthood poses many challenges to overcome in terms of threats to survivors' relationships, sense of self, feelings of security, control, future, fertility, appearance, work and finances. Young adults in this study displayed resilience and positive adjustment in the face of these threats. A novel theory is presented, which explains both positive and negative trajectories involved in adjusting to the threats of cancer in young adulthood, in those with a good prognostic outcome. The theory indicates ways of promoting positive adjustment in younger adults and suggests strategies to help negatively adjusted patients to reframe their illness and better self-manage. The identification of these adjustment processes as well as younger adults' preferences for support has important implications for the delivery of care and future interventions:

Firstly, clinical nurse specialists or other nurses / health professionals who provide psychosocial support to patients could use the framework of the model to identify areas of poorer adjustment and suggest ways of supporting patients better. In particular, the model could be used to prompt them to challenge negative perceptions and shape positive ones, advise on how to cope with ongoing symptoms, support patients with fertility and recurrence concerns, help patients to accept and normalise body image issues, and facilitate peer support through introducing patients who are having treatment simultaneously.

Secondly, the findings have implications for the support and information given to younger adults around and following the end of treatment to better prepare patients for the transition to survivorship. Information that is age and gender relevant is required to prepare survivors for the end of treatment, such as information on fatigue, fertility, contraception use, alcohol intake, 'what is normal' and their expected recovery trajectory as well as signposting to services.

Thirdly, interventions such as one-on-one peer mentoring, patient navigation, exercise, mindfulness or psycho-educational interventions might be particularly useful at promoting positive adjustment and better self-management. Interventions that offer informal support might be particularly useful, especially amongst younger male survivors. Further research is warranted into development of such interventions in samples of younger adults.

Overall, these findings make a significant contribution to our understanding of how younger adult cancer survivors adjust to the psychosocial impact of cancer during the transition from treatment to follow-up, specifically for testicular cancer and Hodgkin lymphoma survivors.

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Appendix

1. Participant invitation letter

(*Hospital letterhead)*

Dear Patient,

Research study: **"Understanding the experiences and needs of younger adults with testicular cancer or lymphoma following initial treatment"**

We are writing to ask if you would like to take part in a research project that is being carried out which aims to better understand the experiences and needs of younger patients with cancer once treatment has ended and over the following 6 months. The study is being conducted by a PhD Student at Oxford Brookes University (Lauren Matheson).

Taking part in the study would involve your talking to the researcher on two occasions; firstly within a month or two following the end of your treatment, and then again approximately 6 months later. During the interviews you will be asked about your experiences and needs (for example, need for information or support services) following the end of your cancer treatment. The researcher could meet you at your home or any alternative quiet location, wherever you prefer. The interviews would last approximately one hour each.

If you are interested in taking part in this research study, it is important for you to understand why the research is being done and what taking part will involve. Please take time to read the information sheet enclosed and discuss it with others if you wish. If you would like to take part, or would like more information first, then please contact the researcher, Lauren Matheson, by sending back the response form in the freepost envelope provided with a telephone number(s) that Lauren can contact you on. Alternatively, feel free to text, email or telephone Lauren if that is more convenient for you.

It is entirely up to you whether you want to take part in this study. If you decide you want to take part, you are free to withdraw from the study at any time, without giving a reason. Whatever your decision, it will not affect any current or future care you receive.

Yours sincerely,

(*Signature and contact details of Clinician*)

2. Research participant information sheet

Research study: **"Understanding the experiences and needs of younger adults with testicular cancer or lymphoma following treatment"**

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what taking part would involve. Please talk to others about the study if you wish and ask us if you have any questions on anything that is not clear. Relevant contact details are at the end of this form. Part 1 will inform you about what taking part in the study will involve. Part 2 provides more detailed information about the study.

PART 1

What is the purpose of the study?

There has been very little research into the experiences and needs of younger adult patients with lymphoma or testicular cancer once treatment has ended and over the following six months when patients start attending follow-up appointments. The aim of this study is to get a detailed understanding of the experiences and needs of younger cancer patients during this recovery period following treatment, in order to find ways of supporting patients better in the future.

Why have I been invited to take part?

You have been invited to participate because you have recently finished treatment for either lymphoma or testicular cancer, and were diagnosed between 20 and 45 years of age. For this study, we will be recruiting approximately 30 patients.

Do I have to take part?

The decision regarding whether or not you wish to take part is entirely voluntary. If you agree to take part you will be asked to sign a consent form. However, you are free to withdraw from the study at any time without having to give a reason. Your decision to take part will have no impact on your current or future medical care in any way.

What will happen to me if I take part?

The study will involve taking part in **2 separate interviews** with a researcher (Lauren Matheson). The researcher is a PhD student from Oxford Brookes University. If you agree to take part, the researcher will call you to arrange a convenient time and date for the interview, and will take place in **a location that suits you** (i.e. your home, place of work or a quiet cafe, for example). The first interview will take place **ideally within 1-3 months following the end of your cancer treatment**. The second interview will take place approximately **6 months later**. Each interview should take approximately **one hour**. If you would prefer just to be interviewed on 1 occasion as a once-off, you would still be welcome to take part in the study. During the interviews you will be asked about your experiences and needs (for example, need for information or support services) following the end of your cancer treatment and the impact on your life (for example, work, relationships, and social life). At the end of the first interview you will be asked to complete a brief demographic questionnaire (for example, your age, education). Following both interviews you will be asked to complete a short questionnaire regarding how you are feeling. This should take around 5-10 minutes. To help us to remember what you say in the interview, we will ask your permission to digitally record our conversation. We will reimburse you for any travel expenses you may have from attending the interview.

What are the possible disadvantages and risks of taking part?

Talking about your experiences of cancer may be upsetting for you. During the interviews, you do not have to answer anything that you don't want to, and you are free to say as much or as little as you want. You are free to stop the interview at any time, without giving a reason. If you decide to withdraw, all of your data will be destroyed. If you need further support at any time whilst taking part in the study will be offered support from an appropriate person, such as your clinical nurse specialist.

What are the possible benefits of taking part?

There may be some benefit to you in the future, as we hope that the results of the study will help improve the support given to people who have had cancer between the ages of 20 and 45. Some people can also find it helpful to talk to someone about their experiences of having cancer to someone who is neither a member of the clinical team nor a friend or relative.

If the information in Part 1 has interested you and you are considering taking part, please read the additional information in Part 2 before making any decision.

PART 2

Will what I say in this study be kept confidential?

All of the information that you give us will be kept strictly confidential. Your consent forms will be kept in a locked filing cabinet at Oxford Brookes University. The interview will be transcribed word-for-word, however any information which could be identifiable, (such as names, places) will be made anonymous. We will replace your name with a participant number. Your interview and personal data will be kept on password protected computers and will not be viewed by anyone outside the research team at Oxford Brookes University (Lauren Matheson, Prof Watson, Prof Boulton and Dr Lavender). With your permission, we may use some direct quotations from the interviews in future publications, however these will be strictly anonymous and will not include any information where you could be identified in any way. Data generated by the study must be retained in accordance with University policy, so your interview data will be kept securely for ten years after the study has ended. Once we have been in touch with you to arrange the second interview (6 months later), your personal details will be deleted. Your clinician will not be aware of what you said during the interviews; however a summary of all of the interviews (not including any names) will be fed back to the healthcare teams participating in the study. They will not know which individuals taking part in the study made which comments.

What should I do if I want to take part?

Please complete and return the response form in the stamped addressed envelope enclosed as soon as possible so we can call you to arrange an interview date. **Alternatively, you can text, email or phone the researcher** directly if this is easier for you (see contact details at the end). Please could you get in touch with us in the **next two weeks, if possible** as we would ideally like to interview patients within a few months following the end of treatment.

What will happen to the results of the research study?

The results of the study will be written up for a PhD thesis and will also be published in academic journals. Any publication of the findings will be completely anonymous (you will not be identified in any way). If you would like a summary of the findings, we can send this to you once the study is over. The findings will be also presented to clinical departments participating in the study and at relevant conferences.

Who is organising and funding the research?

The research is part of a PhD project by Lauren Matheson, who is working in the Cancer Care Research Group in the Department of Clinical Health Care. She is supervised by Professor Eila Watson, Professor Mary Boulton and Dr Verna Lavender. The project is funded by Oxford Brookes University. We have also had assistance from patient representatives from the Thames Valley Cancer Network Consumer Research Partnership.

Who has reviewed the study?

The project has been approved by the Faculty Research Ethics Committee at Oxford Brookes University and the NHS Research Ethics Service (NRES) Committee South Central – Oxford C.

What will happen if I want to withdraw from the study?

If you decide you no longer want to take part in the study you can text, email or phone the researcher or another member of the research team at any time.

Contact details for Further Information

For more information or any questions you have, please contact the researcher **Lauren Matheson** on **01865 482745** or **[mobile phone number removed]** or **lauren.matheson-2011@brookes.ac.uk** (Department of Clinical Health Care, Oxford Brookes University, Jack Straws Lane, Marston, Oxford OX3 0FL). Alternatively, you can contact the project supervisors; Professor Mary Boulton (01865 485298), Professor Eila Watson (01865 482665) or Dr Verna Lavender (01865 483921). If you should have any concerns about the way in which the study has been conducted (study number 2011/12), you should contact the Chair of the Oxford Brookes Faculty Research Ethics Committee Hazel Abbott on 01865 48 2639 or heabbott@brookes.ac.uk.

Should this study have raised any particular issues for you in relation to cancer you may wish to contact your Clinical Nurse Specialist (*insert name and contact details*). In addition, you may wish to contact Macmillan Cancer Support www.macmillan.org.uk, 0808 8080000 and/or your local Maggie's Centre, Tel: 01865 225690 (www.maggiescentres.org) and/or the Lymphoma Association, www.lymphomas.org.uk or Tel 0808 808 5555. These organisations can provide information and support for people with cancer and their families.

Thank you for taking the time to read this information sheet and please contact us if you have any further questions.

3. Response form

Research project: **“Understanding the experiences and needs of younger adults with testicular cancer or lymphoma following initial treatment”**

I would be interested in taking part in the above research study. Please contact me to answer my questions and arrange setting up an interview time.

____
____
Please print name Signature

Name: ____________________________________

Address: ____________________________________

____

____

Tel no: _______________________ (Home)

________________________(Work)

_______________________ (Mobile)

Email: _____________________________________

Please return this form in the freepost envelope provided- thank you

Alternatively you can contact the researcher (Lauren Matheson) by text, phone or email on **01865 482745** or **[mobile phone number removed]** or
lauren.matheson-2011@brookes.ac.uk

4. Consent form

CONSENT FORM

Title of Project: **"Understanding the experiences and needs of younger adults with testicular cancer or lymphoma following initial treatment"**

Name of Researcher: Lauren Matheson **Please initial box**

1. I confirm that I have read and understood the information sheet dated 19/06/13 (version 3.0) for the above study and have had the opportunity to consider the information and ask questions. I have had my questions answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, and without my medical care or legal rights being affected. ☐

3. I agree to take part in the above study. ☐

4. I understand that any data generated in the course of the research will be retained in accordance with the University's policy of Academic Integrity and will be kept securely in paper or electronic form for a period of ten years after the completion of the research. ☐

5. I agree to the interview being recorded and transcribed. ☐

6. I agree that any quotations from my interview can be used anonymously in the presentation of the overall research findings, including journal publications and feedback to relevant health professionals. ☐

7. I am happy for my clinical team to forward details of my treatment and diagnostic information to the research team at Oxford Brookes. ☐

8. I would like to receive a written summary of the study findings.	**Please <u>tick</u> box** Yes No ☐ ☐

________________________ _________________ ________________

Name of Participant Date
Signature

________________________ _________________ ________________

Name of Researcher Date
Signature

(*One copy for participant, one copy for researcher*)

5. Participant demographics form

Participant Reference Number ____________________

Please tick the appropriate box.

Gender: M ☐ F ☐

Age: ________________________ **Date of Birth**__________________

Current Working Arrangements: Which of these best describes your current situation?

Please tick the one that most applies.

☐[1]	In full-time paid work (including self-employment)
☐[2]	In part-time paid work (including self-employment)
☐[3]	In full-time education or training (including government training programme)
☐[4]	Not seeking employment (e.g. Caring for dependent children or adults)
☐[5]	Unemployed
☐[6]	Other: *please specify:*

Are you currently off work because of your illness?

☐[1] Yes
☐[2] No
☐[3] Not applicable

Occupation: Please describe your current/most recent occupation:

____

Ethnicity: To which of the following ethnic groups would you say you belong?
Please tick one box

☐[1]	White British
☐[2]	White Other
☐[3]	Black – Caribbean
☐[4]	Black – African
☐[5]	Black – Other Black
☐[6]	Indian
☐[7]	Pakistani
☐[8]	Bangladeshi
☐[9]	Chinese
☐[10]	Other: *please specify:*

Education: What is the highest level of qualification you have?

Please tick one box.

- ☐1 'O' level (GCSE or equivalent)
- ☐2 'A' level (or equivalent)
- ☐3 Clerical/commercial qualification
- ☐4 College or university degree
- ☐5 Postgraduate qualification
- ☐6 None of these

Marital status: Please describe your marital status**:**

- ☐1 Married
- ☐2 Single
- ☐3 In a relationship
- ☐4 Divorced/separated
- ☐5 Widowed

Living arrangements: Please describe your living arrangements *(tick as many as apply)*

- ☐1 Live alone
- ☐2 Live with parents
- ☐3 Live with spouse/partner
- ☐4 Live with Children

Summary of findings

If you would like to receive a summary of the findings, please provide your name and address and/or email address:

6. Interview schedule (Time 1)

Thanks for volunteering to take part in this research study. The purpose of this interview is to ask you about your experiences and needs now that you have finished your cancer treatment and then to interview you again in around 6 months' time. We hope that this information will be used to help to support younger adults better in the future.

Just to remind you that everything you say will be treated in strict confidence, and you don't have to answer anything you are not comfortable talking about.

Can I ask check that you know what you say will be anonymised- and we won't be telling your nurse or clinician what you said?

Do you understand that you are free to stop the interview at any time if you want, and if you don't want to carry on you don't have to? We can also stop the interview for a short time if you need to have a break.

Do you have any more questions you would like to ask?

Questions

Although the focus of this interview is about your current experiences and needs now you have finished your cancer treatment, could you start from the beginning and tell me about your experience of cancer from when you first heard about your diagnosis?

> **Can you tell me about your experience of completing cancer treatment?**
>
> > (Prompt: *what's it been like since then? how long ago, what happened at the end of treatment – who did you see, how did you feel, did you feel as you expected*, *experience of finishing treatment e.g. emotions, thoughts, overall experience*)

- How did you feel about ending treatment? (*How did you feel once the surgery was over? Did you feel as you expected to feel*? *How prepared did you feel*?
- What was your experience of your last appointment/any follow-up appointments? Were you told anything at the end of treatment, if so what? Did they give you any advice on anything?
- Were you told anything about the future in terms of what to expect?
- How have you found talking to your clinician/nurse? (Prompt: *during and since treatment? Are the issues that are important to you discussed or not? Any problems/challenges*?
- How have you felt, in terms of confidence since finishing treatment? (*Has this changed?)*
- How confident do you feel in terms of asking for support/advice?
- Has the support (from hospital, family etc) changed since the end of treatment? If so how? How do you feel about this?
- How do you feel about having to return for follow-up appointments?
- What was your experience of getting the 'all clear'? How did you feel before/after?

Can you tell me about the impact of cancer on different areas of your life since finishing treatment? (prompt: *impact on how you feel about yourself, how has having cancer affected your work life, home life, finances, how you feel about your body, social life, family and relationships with others, sexual/romantic relationships, feelings towards the future*)

- **What has it been like since ending treatment?** (*how do you feel? What has your experience been like since treatment finished? What has changed*?)

Has there been an impact on..

- How you feel about yourself?
- Your physical wellbeing (how you feel physically?)

- Your home life? Has it impacted on your family/partner/children? If so, how react? How do they cope with it?
- Your social life and relationships? How has it impacted on friends? How have they coped? How have others reacted? How dealt with this?
- Has it had an emotional impact on you? (Has it affected your feelings? Have you felt worried or down at all?)
- Your work? How has returning to work been for you?
- How you feel about your body, and your body image?
- Has it affected your confidence? Are there areas where you feel more or less confident? What do you think affects this? How has this changed?
- Has it affected your thoughts about the future? Future plans? How do you think about the future? Has this changed at all?
- Positive aspects of experience? What have you taken from the experience, if anything?
- So other people have talked about concerns about treatment potentially having an impact on future fertility, is this something you've thought about all? (what were you told? What concerns?)
- How do you think being a young person has affected your experience of cancer? Are there any specific challenges that you think younger people with cancer face?
- What are the main difficulties or challenges you have experienced following your cancer treatment?

- Most challenging thing? (Before finishing treatment, after and currently?)
- How do you cope with these difficulties (*on a day to day basis*)? (Prompt: *how do you deal with the specific challenges, do you feel you manage effectively/as well as you could be?*)
- What sorts of things have helped you to cope? (Prompt: *support from friends, family, health care professionals; what is the most important thing that has helped you adapt to living with cancer?*)

- Do you feel you have changed at all since having cancer? Feel changed since before/ after treatment?
- So looking forward, how do you feel about the next few months?
- How significant do you think having cancer has been for you in your life?
- How do you feel about the fact that TC/or HL is a very curable cancer? Do you think that has affected your experience/thoughts/emotions?

Are the any areas where you felt you wanted more information/ or support?

- Anything that could have helped you deal with things better?
- Has there been anything that has been unhelpful?
- Do you have any unanswered questions?
- How do you think the support at the end of treatment could be improved, if at all?
- Is there any support that you feel you need now treatment is over? If so what?

What do you think might help younger adults in the future?

- From your own experience and for younger adults in general?
- How could support be improved at the end of treatment at discharge interview?
- At follow-up? And at different times after treatment?
- What are your views/experiences/thoughts towards- support groups, internet forums, mentoring/peer support, buddy systems, support groups just for younger adults?
- What advice would you give to others who may be dealing with this?

Is there anything else you would like to add that I haven’t asked you but you think is important, or anything else you think I’ve missed?

7. Interview schedule (Time 2)

Thanks for volunteering to be interviewed for a second time. I just want to ask you similar questions to the first interview to find out about your experiences and needs at the moment, and how these have changed over the last six months. I just want to remind you again that everything you say is completely confidential, and you don't have to answer anything you are not comfortable talking about. Just to remind you that you are free to stop the interview at any time. You can have a break anytime during the interview.

Can you tell me how the last 6 months has been for you? (further treatment needed? What was that like? How did you feel about that treatment ending?)

- How have you found being on a follow-up regime (Prompt: *Are the issues that are important to you discussed or not? Any problems/challenges*, *what could be improved? What is the most vital aspect of care*?)
- How do you feel about having to return for follow-up appointments?
- How have you found talking to doctors/nurses? (any problems/challenges?)
- Has anything changed in the last six months? If so, what has changed? (Prompt: *what has changed in terms of your needs, experiences*?)
- What are you told at follow-up appointments? (any advice given? Were you told about the future in terms of what to expect?)
- How have you felt in terms of confidence since finishing treatment? (*how confident do you feel asking for support*?)
- Have you been referred anywhere else for support?

Can you tell me about the impact of cancer on areas of your life at the moment? (prompt: *impact on how you feel about yourself, how has having cancer affected your work life, home life, finances, how you feel about your body, social life, family and relationships with others, sexual/romantic relationships, feelings towards the future*)

- What has changed over the last 6 months?
- How you feel about yourself?
- Your physical wellbeing (how you feel physically?)
- Your home life? Has it impacted on your family/partner/children? If so, how react? How do they cope with it?
- Your social life and relationships? How has it impacted on friends? How have they coped? How have others reacted? How dealt with this?
- Has it had an emotional impact on you? (Has it affected your feelings? Have you felt worried or down at all?)
- Your work? How has returning to work been for you?
- How you feel about your body, and your body image?
- Has it affected your confidence? Are there areas where you feel more or less confident? What do you think affects this? How has this changed?
- To what extent do you worry about your health in the future?'
- Has it affected your thoughts about the future? Future plans? How do you think about the future? Has this changed at all?
- Positive aspects of experience? (has your view on this changed at all?) What have you taken from the experience, if anything?
- So other people have talked about concerns about treatment potentially having an impact on future fertility, is this something you've thought about all? (what were you told? What concerns?)
- How do you think being a young person has affected your experience of cancer? Are there any specific challenges that you think younger people with cancer face?
- What are the main difficulties or challenges you have experienced following your cancer treatment?
    - Most challenging thing? (Before finishing treatment, after and currently?)
    - How do you cope with these difficulties (*on a day to day basis*)? (Prompt: *how do you deal with the specific challenges, do you feel you manage effectively/as well as you could be?*)

    - What sorts of things have helped you to cope? (Prompt: *support from friends, family, health care professionals; what is the most important thing that has helped you adapt to living with cancer?*)

- Do you feel you have changed at all since having cancer? Feel changed since before/ after treatment?
- So looking forward, how do you feel about the next few months?
- How significant do you think having cancer has been for you? (*as something that has happened to you in your life*) How do you feel about the illness now?
- How do you feel about the fact that TC/or HL is a very curable cancer? Do you think that has affected your experience/thoughts/emotions?

Are the any areas where you felt you wanted more information/ or support?

- Anything that could have helped you deal with things better?
- Has there been anything that has been unhelpful?
- Do you have any unanswered questions?
- Is there any support that you feel you need now treatment is over? If so what?

What do you think might help younger adults in the future? (once treatment is over?)

- From your own experience and for younger adults in general?
- How could support be improved at follow-up?
- What are your views/experiences/thoughts towards- support groups, internet forums, mentoring/peer support, buddy systems, support groups just for younger adults?
- What advice would you give to others who may be dealing with this?
- Do you think talking about the experience has helped in any way?

Follow up on specific issues discussed at Time 1 for each participant

- *Example questions*- You talked about the doctor warning you of a delayed emotional impact- has this been an issue for you?
- What do you think about a system whereby people who have been through treatment could support others?
- Has tiredness still been an issue for you? Has this been addressed? How have you managed this?

Closing the interview

Thank you very much for your time. That's been really interesting.

Is there anything else you would like to add that I haven't asked you but you think is important, or anything else you think I've missed?

8. Example of initial and focused coding on an interview transcript

Initial coding	**Testicular cancer patient interview extract** *(P- participant, R- researcher)*	**Focused coding**
Perceiving end of initial treatment as routine Comparing end of treatment experiences (initial vs. recurrent) Finishing treatment for a recurrence a greater milestone Feeling pleased over good outcome Having the opportunity for reflection over life after cancer Being aware of cancer ‘clichés’	*P: ‘the first one [end of initial treatment] felt routine, it should work, 99%, it should work so, yeah we had a little bit of a celebration and it felt good, but yeah it was a bit of a non-entity, you know, this time round, in terms of getting through the treatment and finishing treatment, a massive milestone, in terms of getting told, it’s just the best thing, I think really in terms of I don’t know, in terms of the whole being told and trying to understand what you’re gonna go through and I think you kind of, you have this massive moment of reflection, people it might be a cliché but it puts things in perspective which it does, to actually know that there’s a positive outcome at the end of it is*	Evaluating the significance of the initial vs recurrence treatment Gaining a sense of perspective over life

Putting life into perspective Feeling ecstatic at end of treatment over positive outcome Comparing changes after initial vs recurrence treatment completion – knowing recurrence led to more serious implications (fertility) Needing more time to recover after chemo treatment for recurrence Feeling resentment over having cancer despite curable nature of disease Trying to accept cancer experience Experiencing mixed	*yeah, pretty mind blowing, it's just like an ecstatic feeling, but obviously the problem, the first time round it put me in to the same position I was before pretty much, this time round after the chemotherapy obviously there was still some recovering to do, and then obviously from.. having children there was complications from there, and so it's a bit of a let-down to know, it's like oh.. yeah I'm curable, but I'd prefer all this not to have happened to me anything, so there's still a slight feeling of resentment strangely* *R: resentment against?* *P: against having it in the first place, yeah it's gonna happen to someone, so you just have to go through it I suppose, but yeah so it's a massive feeling of ecstasy but coupled with still just a small feeling of resentment because things have changed… so yeah'*	Holding positive perceptions over curability of cancer Evaluating the significance of having treatment for initial vs recurrent disease Resenting the impact to fertility- struggling with disruption to developmental milestones Resenting the impact to fertility- struggling with disruption to

feelings of resentment and ecstasy at end of treatment Having a changed sense of normality after cancer- impact of altered fertility status Being frustrated over long period of inactivity and inability to play sports Expecting to have lost more weight on chemo Being frustrated by weight gain and difficulty in recovering fitness Realising fitness is lower than ever before Having to go through IVF Struggling to get funding due to wife's age Fertility issues add	*R: and are there any other challenges for you at the moment?* *P: I think the one frustrating one is that I haven't played sport for 6 months, and with Dr [name] anti sickness been so good I haven't lost as much weight as I was hoping to, I was hoping to shrink down to about [weight] and then just be able to get fit from there but it hasn't happened and trying to aid my recover by eating well and I've just gone outwards so yeah that's a bit of a frustration, fitness levels have dropped down to a level that I've never known before which is a pain, so that's a frustration, on another subject we've.. wife and I have had to go to the IVF clinic and go through counselling and jump through the various hoops for funding, apparently she's too young, they only fund certain ages to keep the numbers down, so whilst we feel we've been given a*	developmental milestones Striving to restore a normal body self Striving to restore a normal body self Resenting the impact to fertility- struggling with disruption to developmental

to burden to self and wife Feeling unlucky over loss of fertility- a ‘shitty set of cards’ Losing fertility magnifies the significance of cancer Feeling route to parenthood should be right of passage Having a sense of unfairness over disruption to parenthood Watching others becoming parents is challenging for self and wife Trying to protect and support wife emotionally over issue Cancer destroying dreams of partner and self Feeling parenthood the next stage in relationship	*pretty shitty set, hand of cards, um it’s almost yeah, it’s almost been, magnified by the fact that we’ve got to go through these processes which we thought well you know.. it should be our right we should just be able to crack on and do this and we can’t and so yeah, that’s obviously been another challenge as it were, friends and family, cousins and stuff getting pregnant left right and centre, it’s been a bit of an effort to sort of stay, keeping my wife as positive as possible and looking after her, yeah her state of mind, in terms of that, because I think we’ve been married for a few years now and we’ve got the stage where we kind of feel that we’re all set up and that’s the next logical step and it should be an easy transition and it’s not, it’s not for us, that’s a tough one…’*	milestones Weighing up the significance of cancer Resenting the impact to fertility- struggling with disruption to developmental milestones Protecting the spouse Resenting the impact to fertility- struggling with disruption to developmental milestones

9. Example of focused coding and theoretical coding on an interview transcript

Focused coding	**Hodgkin lymphoma interview extract** *(P- participant, R-researcher)*	**Theoretical coding**
Learning to accept emotions Positive perceptions over illness Making comparisons to worst case scenario	*R: have you felt down at all since the treatment?* *P: yes and I think sometimes part of it has been external things but I think also, you can feel down and then you can feel cross with yourself for feeling down because you feel that you shouldn't feel down because your back in remission and your back in your normal life so you kind of have that extra thing where especially if it's a relatively little thing, cos one of the good things that happened last year was that I was so pleased to be able to be treated for something, you know it could have been a lot worse and to be in*	Needing to find a balance between changed perspective and the reality of life Holding onto positive illness perceptions (treatable, curable disease) Reframing the illness through social comparisons

Becoming more tolerant over ‘trivial’ issues in life	*remission and I was so happy about that, that I was really kind of tolerant of any bad things happening so really down to the little things, so being stuck in a queue somewhere, which before would have irritated me, oh another queue.. with everything that happened last year you think very zen like, you think at least I’m out and about I’m still here, I don’t care if there’s a queue but*	Having an enhanced sense of personhood
Realising changed perspective gets lost in ‘normal’ life	*actually that kind of perspective can get lost when you get back to normal life and a few times particularly in the last few months*	
Finding a middle ground between changed perspective and the reality of life	*thinking ohh this annoying thing again and then you think I really shouldn’t be getting worked up about this, and thankfully I’m usually able to think it’s not really a big deal in the grand scheme of things, but sometimes if you feel a bit sad about something you can then, you have this guilt for*	Needing to find a balance between changed perspective and the reality of life

Realising emotions unrealistic in day-to-day life Adjusting altered perspective – accepting real emotions to day-to-day events Having a sense of recovering well from cancer	*thinking well I shouldn't really feel sad about it, cos I shouldn't feel sad about anything I'm still alive I'm still here, so I should be grateful to be here, I haven't got the rights to feel sad about anything… like sad about not getting a promotion, I shouldn't feel sad about that cos I should still be here, but then the thing is you can't live the rest of your life like that, you have to sort of just get on with it and say no I do deserve to have that promotion or I do I should go off and do this thing, so yeah it's complicated [laughs]* *R: so maybe at times then you might feel down?* *P: yeah at times, I think it's not.. um usually to do with…I'm not aware that it's to do with the cancer directly because I feel as if I've come out of it, fingers crossed, I feel as if I've come out*	Holding positive illness perceptions

Struggling to accept loss of long hair Struggling to accept appearance change- comparing to ‘healthy’ women Feeling supported by partner over appearance changes	*of it pretty well, I do sometimes miss my long hair that I use to have.. but then you start thinking well I can’t complain about that because… that sort of thing, but yeah things like that especially I think [months] when my hair was still really really thin and it was obvious that something had happened to it, it didn’t look quite right and I went out with my boyfriend and he was surrounded by all these women who had beautiful hair and I remember thinking, feeling quite upset actually and thinking my hair isn’t like that, but it will probably come back to what it was before, and he was there saying I don’t care about that, I still like you anyway so you’ve got that to counteract it*	(recovery) External support by partner- helping to accept appearance changes

Example A illustrates how categories were often constant over Time 1 and Time 2 in many instances. In this participant, the category of ‘*accepting cancer as part of life trajectory’* was seen in both interviews. There were however, subtle differences in codes which related to this theme. At Time 2, whilst many views were the same, this participant struggled with accepting the impact on her appearance, which had not been evident at Time 1. This was influenced by her re-integration into work and community roles, which affected self-confidence. Example B illustrates how themes could significantly change from Time 1 to Time 2. In another participant, at Time 1, she described feeling confident at dealing with anxiety over a recurrence. At Time 2, she recalled periods of struggling to cope with anxiety since the first interview.

10. Longitudinal analysis: similarity of themes over time (example A)

Time 1	Time 2	Longitudinal Themes
Accepting cancer as part of life trajectory *Accepting a cancer diagnosis in younger adulthood as a normal event affecting many others*	**Accepting cancer as part of life trajectory** *Striving to accept appearance issues* *Struggling with appearance issues in work and community roles*	**Accepting cancer as part of life trajectory** *Ongoing acceptance of cancer as part of life trajectory, although struggling to accept impact on appearance at times*

11. Longitudinal analysis: evidence of change over time (example B)

Time 1	**Time 2**	**Longitudinal Themes**
Adjusting to a new normal in psychological wellbeing *Normalising anxiety over physical symptoms* *Getting on with it approach to managing feelings*	**Escalating anxiety** *struggling to adjust to loss of security after treatment completion* *feeling alone to deal with anxiety* *striving to recover psychological wellbeing*	**Striving to restore a sense of security**