

**A LEGACY OF LINGERING UNCERTAINTY.
THE EXPERIENCE OF LONG-TERM CANCER SURVIVORSHIP:
A MULTIPLE-CASE STUDY**

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Abstract

More people are surviving cancer, and for longer. As a result, 'cancer survivorship' is a key policy and research issue. However, there is a lack of research looking at experiences of long-term cancer survivorship. This exploratory study aimed to describe the cancer experience of individuals living five years or more post-treatment. Moving beyond description, it also sought to investigate the utility of existing frameworks for developing our understanding of the cancer experience.

A multiple-case study design was adopted. A narrative interview and semi-structured follow-up interview were held with thirteen participants who were five years or more post-treatment. Interviews were also held with their 'significant others'. Analysis took a holistic-content approach, underpinned by the three-dimensional narrative inquiry space. The 'restorying' of individual narratives was followed by a cross-case analysis to explore similarities and differences across cases, to describe the experience of long-term survivorship at the aggregate level. The study went on to explore the utility of liminality as a framework for understanding experiences of long-term survivorship. Little *et al.* (1998) identified 'elements' of the liminal experience: 'cancer patientness', 'communicative alienation' and 'boundedness'. They also argue that individuals live in a state of 'sustained' liminality that persists until the end-of-life. Whilst a small body of research supports this assertion, it has been suggested some individuals may 'transcend' the liminal phase. Limitations to existing research suggested a need to explore these assertions further with those living long-term after a cancer diagnosis.

Individuals diagnosed with breast, gynaecological, prostate, testicular and colorectal cancer, five to sixteen years post-treatment, took part in the study. Cancer has left a legacy of benefits and losses. In particular, a legacy of *lingering uncertainty* is evident across cases. The most common manifestation

is fear of recurrence. A typology of the place of cancer was developed. At the time of interview, cancer was situated in the *past, past-present or present-future* for participants. However, the place of cancer is not static. It oscillates between the past, present and future, and foreground and background of participants' lives as a result of the lingering uncertainty and various '*reality checks*' experienced.

Most, but not all, participants live in a state of 'sustained' liminality. Perceiving the five-year survival marker as a '*milestone*' is key to transitioning out of the liminal state. Some participants have put cancer (the disease) in the past, but consequences of treatment that affect physical functioning result in them living in an on-going state of liminality - on the threshold between 'sickness' and 'wellness'. Others perceive they are living with cancer *within* them, and therefore experience liminality existentially. A sense of 'boundedness' is particularly evident in these narratives, as a result of limits imposed on social functioning and not feeling free of cancer. However, whilst liminality is often construed negatively, it can be a catalyst for positive change to self, outlook on life and relationships. Exploring intrapersonal, interpersonal and societal factors helped unpick why some individuals appear to successfully move beyond cancer, whilst others struggle to do so.

This thesis makes several contributions to new knowledge. It presents a narrative understanding of the experience of those living long-term after a cancer diagnosis, complimenting the 'distress' focus of much psycho-oncology research. With little UK-based research on the experience of those living five years or more post-treatment, this exploratory study lays the foundations for further exploration of the illness experience in this population. It also makes a theoretical contribution as research had not previously explored liminality and the experience of those specifically five years or more post-treatment. Implications for practice are positioned within the context of new models of 'aftercare' being implemented. Holistic needs assessments at key transition

points along the survivorship trajectory are crucial to providing tailored care within the context of individuals' wider lives.

Publications

Blows, E., Bird, L., Seymour, J. and Cox, K. (2012) Liminality as a framework for understanding the experience of cancer survivorship: a literature review. *Journal of Advanced Nursing*, 68 (10) 2155-2164. .

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A note on terminology

Long-term cancer survivors

The term 'cancer survivor' is a contested one, as will be highlighted in this thesis. I use the terms '*participants*', '*individuals living long-term after a cancer diagnosis*' and '*those five years or more post-treatment*' rather than '*cancer survivors*' when referring to the individuals who participated in this study.

Chapter 1. Background, Research Aims and Thesis Structure

Study background and rationale

Cancer survival

Improved screening, and thus earlier detection, and the development of more effective treatments, have led to an increase in the number of people surviving cancer. The Lance Armstrong Foundation reports that there are now twenty-eight million cancer survivors worldwide¹. In the USA, there are an estimated 13.7 million cancer survivors² (American-Cancer-Society 2012). This is in contrast to just three million survivors in 1971³. Sixty-four percent of survivors in the USA were diagnosed over five years ago, and 15% were diagnosed over twenty years ago (American-Cancer-Society 2012). There are approximately two million cancer survivors in the UK. Of these, 1.24 million (62%) were diagnosed more than five years ago (Maddams *et al.* 2009). The number of survivors is increasing by approximately 3% per year. Therefore, it is predicted that, by 2030, there will be over four million cancer survivors in the UK (Maddams *et al.* 2009).

Cancer survivorship as a health policy issue

With more people surviving cancer, and for longer, 'cancer survivorship' is a key health policy issue, as demonstrated by the establishment of government departments and initiatives with a survivorship remit. The Office of Cancer

¹ <http://www.livestrong.org/pdfs/3-0/LS-TherapeuticBrief-FINAL> [Accessed January 12th 2012].

² Americans alive with a history of cancer on January 1st 2012.

³ <http://www.cancer.org/Cancer/news/News/numberofuscancersurvivorsgrowing> [Accessed April 7th 2011].

Survivorship was established in 1996 to improve not just the *length* but also the *quality* of cancer survival in the USA. Its goal is 'to focus on the health and life of a person with a history of cancer beyond the acute diagnosis and treatment phase' (Aziz 2007). Subsequently, the US Institute of Medicine published a report in 2005 - *From Cancer Patient to Cancer Survivor – Lost in Transition* - which highlights the importance of the transition from active treatment to life post-treatment for the long-term health of cancer survivors (Hewitt *et al.* 2005).

In 2007, the Department of Health in England launched the Cancer Reform Strategy, which set a clear direction for cancer services (Department-of-Health 2007). The Strategy includes a chapter on 'Living with and beyond cancer', which highlights the importance of identifying the information, support and service needs of cancer survivors, and how to meet them. To support the survivorship agenda in England, the National Cancer Survivorship Initiative (NCSI) was established in 2008. Similar to the goal of the Office of Cancer Survivorship, the aim of the NCSI is to ensure people affected by cancer receive the care and support they need to lead healthy and active lives, for as long as possible (Department-of-Health 2010). Therefore, alongside improving survival rates, the global focus of survivorship initiatives is clearly on promoting health and wellbeing after a cancer diagnosis.

Cancer survivorship research

The volume of cancer survivorship research has grown substantially over the last thirty years (Harrop *et al.* 2011). The NCSI's Research workstream published its research priorities in 2010, based on a consultation exercise with researchers, survivors and statutory and voluntary organisations (Armes *et al.* 2009b), and an evidence review of health and wellbeing issues, and interventions addressing them (Richardson *et al.* 2009). The evidence review identified substantial research describing 'problems' experienced by survivors

in the period following treatment. However, they found a lack of research addressing longer-term problems and solutions to them (Richardson *et al.* 2009, Richardson *et al.* 2011). Therefore, priority areas for survivorship research in the UK were highlighted as: identifying those at risk of ongoing problems post-treatment, exploring the psychological and social impact of cancer and investigating the ongoing physical symptoms of cancer, experienced as a result of treatment (Richardson *et al.* 2011). These priorities are echoed in a review of survivorship research projects in the USA, which concluded that research is needed in the area of late and long-term effects of cancer (Harrop *et al.* 2011). Those surviving cancer for longer are at greater risk of developing late and long-term effects of cancer and its treatment (Harrop *et al.* 2011). Therefore, as the number of long-term survivors increases, 'it is crucial that investigators make a commitment to understand the unique needs' of this population (Aziz, 2009: 783).

Summary

It is clear that understanding and supporting the needs of the growing number of people surviving a cancer diagnosis is a pertinent policy and research issue. In particular, as more people survive cancer, and for longer, it is important to further our understanding of the experience of living long-term after diagnosis. This can be achieved, in part, by giving individuals the opportunity to articulate their experiences of life during the long-term survivorship phase of the cancer trajectory. However, whilst 'survivorship' rhetoric is now firmly embedded within English health policy, the term 'cancer survivor' is increasingly contested and has led some to question whether it actually resonates with those to whom it refers. It is argued that the terminology requires clarification, not just in terms of defining who and when someone is a 'cancer survivor', but how and by whom the terminology is appropriated. These issues will be discussed at length in this thesis.

Research aim and objectives

This study aimed to describe, and further our understanding of, the experience of long-term cancer survivorship (≥ 5 years post-treatment). Moving beyond description, the study also sought to explore the applicability and utility of liminality (Little *et al.* 1998) as a framework for understanding the experience of long-term cancer survivorship.

The study aimed to meet the following objectives:

1. Describe the experience of long-term cancer survivorship
 - a. Explore how the concept of 'survivorship' has been constructed in relation to cancer, and what 'survivorship' means to those who are living five years or more post-treatment
 - b. Explore the impact of cancer on daily living, self, outlook on life and relationships (the illness experience)
2. Explore the utility of liminality as a framework for understanding the experience of long-term cancer survivorship
 - a. Does the state of 'sustained' liminality (Little *et al.* 1998) reflect the long-term cancer survivorship experience?
 - b. Do participants experience Little *et al.*'s (1998) 'elements' of:
 - i. 'Cancer patientness'
 - ii. 'Communicative alienation'
 - iii. 'Boundedness'
3. If participants live in a state of 'sustained' liminality, explore possible reasons for this. What differentiates those who live in a state of 'sustained' liminality from those who do not?

Structure of the thesis

Chapters 2 to 4 review pertinent literature on experiences of long-term cancer survivorship. The literature review is split into three parts. The term 'cancer survivor' is ubiquitous today, but poorly defined. As such, the first part of the review (Chapter 2) aims to critically explore the concept of 'cancer survivorship' and develop a working definition for the study. Part 2 of the review (Chapter 3) seeks to justify the study's focus on long-term cancer survivorship and critically synthesises existing research on the subjective experience during this phase of survivorship. In particular, the review explores the meaning of cancer and the impact of the disease on identity and relationships. Finally, part 3 (Chapter 4) draws together research that has utilised the concept of liminality to explore the cancer experience, the aim of which was to explore the utility of liminality for understanding experiences of long-term survivorship.

Chapter 5 outlines the methods used in the study. I discuss the philosophical underpinnings of the study, data collection and analytical procedures, and issues pertaining to the quality of qualitative research. The chapter draws on both the methodological literature and my personal reflections on the development of the study.

I present the findings in Chapters 6 to 9. Chapter 6 highlights participant characteristics and provides further detail on the conduct of the interviews. Chapter 7 presents the individual 'restored' accounts of participants' experiences of living during the long-term survivorship phase. The case studies are structured according to broad themes identified in the narratives. Chapter 8 goes on to present a thematic analysis of the 'significant other' accounts, exploring their perceptions of who the person diagnosed with cancer is today and what impact, if any, they feel cancer has had on their loved one's sense of self and relationships with those close to them.

Findings from a cross-case analysis are presented in Chapter 9, the aim of which is to present a series of overarching themes to describe the experience of long-term survivorship at the aggregate level. Individual-case findings are merged through a process of searching for patterns in the 'restored' accounts. The accounts of those diagnosed with cancer and 'significant others' are also compared and contrasted in Chapter 9. The analysis highlights instances where accounts shared by those diagnosed and their loved ones differ and explores what the implications of these contrasting accounts of the cancer experience might be. I go on to discuss the findings in relation to existing literature, highlighting the study's contribution to furthering our understanding of the cancer experience.

In Chapter 10, the discussion moves on to explore the applicability of liminality as framework for understanding the experience of those living long-term after a cancer diagnosis. I draw on the study's findings to make suggestions for theoretical development. In an attempt to persuade readers of the trustworthiness of my research, this chapter also includes a reflexively-based evaluation of quality of the research and reflections on the study's strengths and limitations.

The final chapter, Conclusions (Chapter 11), draws together research, policy and practice to highlight the implications of the findings, and avenues for future research. Implications for practice have been positioned within the context of changes to follow-up care that are currently being implemented in England. I highlight the implications of new models of 'aftercare' for those living in the long-term phase of the survivorship trajectory. Theoretical and societal implications are also considered.

Chapter 2. Literature Review: Part 1 - Defining cancer survivorship

Introduction

Today, the terms 'cancer survivor' and 'cancer survivorship' litter oncology publications, policy initiatives and cancer advocacy and support organisations' websites. Kaiser (2008: 79) describes the term 'cancer survivor' as 'ubiquitous', with those living after a diagnosis of cancer often referred to as 'survivors'. However, it is argued that the terminology requires clarification, not just in terms of defining who and when someone is a 'cancer survivor', but how and by whom the terminology is appropriated. Part 1 of this review discusses the concept of 'survivorship' more broadly and what is it about cancer that attracts the label 'survivor'. I outline the historical development of the terms 'cancer survivor' and 'cancer survivorship' and how the relevance of the terminology has changed over time. I also touch on the key debates surrounding the contested nature of the terminology, including whether being labelled a 'cancer survivor' actually resonates with those to whom it refers. The chapter concludes with working definitions of a 'cancer survivor' and 'cancer survivorship' to be used in the study.

Literature search

Search strategy

Electronic searches of PsycInfo, ASSIA, Web of Science, The Cochrane Library, CINAHL, Medline, British Nursing Index and British Library online databases were conducted in November 2009, and subsequently updated in April 2013. Search terms were: cancer survivorship; cancer survivor*, living with cancer OR remission AND defin*; cancer survivor* AND concept*; survivor* research;

long-term AND cancer survivor*. Databases were searched for literature in the English language, from 1985 onwards. The decision to select works from 1985 was based on the publication of Mullan's seminal work in this year. Mullan (1985) was one of the first to coin the term 'cancer survivor'. Subsequent works have built on, or critiqued, his definition. In addition, lists of references from relevant papers were searched to identify articles that may have been missed during the searches. Alerts were also set up with selected journals to inform me when new survivorship research was published.

Inclusion and exclusion criteria

Literature was included in this section of the review if it:

- Focused specifically on defining the concept of cancer survivorship, cancer survivors or long-term cancer survivors
- Included a discussion of the history of cancer survivorship
- Focused on cancer survivorship research challenges and opportunities
- Focused on cancer survivorship issues, such as consequences of treatment, supportive care, etc. but included discussion of the definition of survivor(ship) and/or difficulties conceptualising the term

Literature was excluded if it:

- Focused solely on childhood/adolescent cancer survivors, as this study focused on survivors diagnosed in adulthood. However, articles were included if they discussed survivorship issues experienced by both childhood/adolescent and adult cancer survivors
- Did not provide a definition of 'cancer survivor' or 'cancer survivorship'

To provide a comprehensive overview of 'survivorship', additional literature was included that discussed 'survivorship' more broadly, for example, surviving natural or man-made disasters and holocausts, and surviving illness.

The concept of 'survivorship'

Surviving life-threatening events

The social and behavioural sciences have been studying 'disasters' since World War II, exploring the individual and collective impact of man-made disasters such as the atomic bomb and Holocaust. Sociologists have also explored the impact of natural disasters, including Erikson's (1976) seminal research on the Buffalo Creek flood. Lifton (1980) explored the concept of survivorship with respect to four holocausts⁴: Hiroshima, Nazi concentration camps, the Vietnam War and the Buffalo Creek flood. Lifton described a survivor as 'one who has encountered, been exposed to, or witnessed death, and has himself or herself remained alive' (1980: 117) and outlined five themes evident in surviving a life-threatening experience (Figure 2.1).

Lifton concluded that 'survivors require expressions of grief and mourning if they are to begin to derive from their experience its potential for some form of illumination. Unresolved, incomplete mourning results in stasis and entrapment in the traumatic process' (1980: 124).

⁴ The Holocaust (the Nazi genocide of Jews) and holocausts (meaning total disaster).

Figure 2.1: Themes evident in surviving a life-threatening experience

'Death imprint' – the 'indelible images' of the experience (1980: 117-118).

'Death guilt' – questioning why they survived whilst others did not. Lifton distinguishes between 'animating' and 'static' guilt patterns. Animating guilt involves drawing insight from the experience, which can lead to positive change, whilst static guilt involves an inability to confront the experience, which prevents change or acceptance.

'Psychic numbing' – 'a diminished capacity to feel' (1980: 120). Initially, this is necessary to protect from being overwhelmed by the experience. However, if the numbing persists, it can lead to apathy, depression and withdrawal.

'Suspicion of counterfeit nurturance' – relates to a desire to regain independence and autonomy. Lifton suggests 'the survivor feels the effects of his or her ordeal but frequently resents help offered because it is perceived as a sign of weakness' (1980: 122).

'Struggle for meaning' – survivors 'seek something beyond economic or social restitution – something closer to acknowledgement of crimes committed against them and punishment of those responsible – in order to re-establish at least the semblance of a moral universe' (1980: 123). E.g. Hiroshima survivors joining peace groups to protest against nuclear warfare.

(Source: Lifton (1980))

Surviving illness

Dow argues that, as a concept, survival has only recently been applied to illness. Survivors of extreme situations such as natural disasters are perceived as 'extraordinary and heroic' whereas those that survive illness do so 'in the context of everyday life' (1990: 511). Dow (1990) highlighted the work of Smith (1979) who conducted interviews with patients with acute medical-surgical, psychiatric and alcohol-related conditions, who had a good prognosis, asking them to describe their experience of recovery. Smith asserted that people who have recovered from serious illnesses can be called 'survivors' (Smith 1979). She defined serious illness 'as an illness that held a realistic threat to physical or psychological health' (1979: 441). As such, Smith offers a different perspective to Lifton (1980), who described survivors as those having faced mortality. Indeed, Smith found that comparing survivors of serious illness to survivors of natural disasters, war, etc. highlighted several

differences. Large groups are affected by flood or war, thus it is a 'shared catastrophe' (1979: 441). Equally, these events are perceived as 'extraordinary', whereas surviving illness is more common and, 'although patients are having similar experiences, each is dealt with primarily as an individual' (Smith, 1979: 442).

Despite their different definitions of what constitutes a 'survivor', Smith (1979) identified similar themes to Lifton (1980). Survivors experience changed values and priorities, and feelings towards others, as a result of a 'heightened awareness of death with a sharp realisation of limited life span' (Smith, 1979: 442). Indeed, she argued that 'awareness of death or a sense of hitting bottom were crucial to perceiving a need to change values, priorities and goals' (1979: 442). Subsequently Smith found negative outcomes were identified in patients who denied their illness or that it had impacted on their lives, those who thought nothing had changed as a result of illness or those not engaged in their own recovery. Indeed, Dow later concluded that 'survivors who were able to derive meaning were able to put the experience into perspective and get on with living' (Dow, 1990: 512).

More recently, Peck (2008) provided a slightly different perspective, suggesting the term 'survivor' can be defined in two ways: a) someone who has survived a *life-threatening* event, such as cancer, a heart attack, earthquake or accident and b) someone who has lived through a *life-altering* event, such as sexual abuse, domestic violence or homelessness (Peck 2008). Based on a review of studies within the nursing, social science and multidisciplinary literature, Peck highlighted six themes that typify the survivorship experience. The survivor:

1. Confronts mortality
2. Experiences alienation and isolation
3. Has a need for support
4. Searches for meaning in the experience

5. Experiences a need to reprioritise their life, including changes to self
6. Experiences continued vulnerability

Surviving cancer – the disease

From a clinical perspective, until relatively recently, ‘cancer’ and ‘survival’ have been somewhat contradictory terms (Breaden 1997). In the 1800s, a diagnosis of cancer was tantamount to a death sentence and patients were rarely informed that they had the disease. Fear of cancer, partly due to the misconception that it was contagious, was widespread. The family rarely divulged a cancer diagnosis, due to the resulting stigma that would be attached to the patient and family (Lewis 2007). It was only during the early twentieth century that surgery improved sufficiently that it was sometimes possible to operate and cure early stage tumours. It was also during this period that education became important. For example, the American Cancer Society was founded in 1913 and made the first attempts to overcome fatalistic attitudes about cancer. Warning signs were publicised and people were encouraged to seek medical advice if they experienced symptoms that might be indicative of cancer (Holland 2002).

Radiation was added as a treatment option in the early twentieth century. Chemotherapy was subsequently added as a third treatment, combined with increasingly effective surgery and radiation in the 1950s. Effective treatment regimens helped reduce pessimism about cancer as survival rates improved. This resulted in a shift to exploring the longer-term effects of treatment (Holland 2002). Further treatment and screening advances continued during the second half of the twentieth century, including the development of targeted therapies, such as endocrine therapies, and genetic testing.

The late twentieth century saw concern shift to cancer prevention, screening and lifestyle change as survival rates continued to improve. Society had witnessed a shift from the nineteenth century view of cancer being

tantamount to a death sentence and the patient bearing no responsibility for developing the disease, to the twenty-first century position where five-year survival rates for some cancers are over 90%, and the onus is placed on individuals to adopt healthy living practices to reduce their cancer risk.

Today, approximately 320,500 new cases of cancer are diagnosed in the UK each year⁵. Breast, lung, colorectal (bowel) and prostate cancer are the most common, accounting for over half of all new cancers diagnosed each year (Table 2.1).⁶ However, Table 2.2⁷ shows that, over the past forty years, five-year survival has increased considerably for some of the most common cancers in England and Wales. Taking all cancers combined, the five-year survival rate is now over 50%.⁸

Table 2.1: Most commonly diagnosed cancers in the UK (2009)

Cancer	Number of cases		
	Males	Females	Total
Breast	371	48417	48788
Lung	23041	18387	41428
Colorectal	22711	18431	41142
Prostate	40841	0	40841

(Source: Cancer Research UK website)

Table 2.2: 5-year survival for common cancers in England & Wales, 1971-75, 2001 & 2009

Cancer	Gender	1971-1975	2000-2001	2009
		5-year survival rate (%)	5-year survival rate (%)	5-year survival rate (%)
Breast	Females	52	81	84.2
Lung	Males	4	7	7.8
	Females	4	7	8.7
Colorectal	Males	22	52	52.4
	Females	23	53	53.6
Prostate	Males	31	71	80.6

(Sources: Cancer Research UK website; Office for National Statistics, 2011)

⁵ <http://info.cancerresearchuk.org/cancerstats/incidence/all-cancers-combined/> [Accessed June 28th 2012].

⁶ <http://info.cancerresearchuk.org/cancerstats/incidence/commoncancers/index.htm> [Accessed June 28th 2011].

⁷ <http://info.cancerresearchuk.org/cancerstats/survival/siteandsex/index.htm> [Accessed December 15th 2011].

⁸ <http://info.cancerresearchuk.org/cancerstats/survival/latestrates/index.htm> [Accessed June 28th 2012].

Therefore, the term 'survivor' has grown in relevance over time, reflecting treatment developments and improved survival outcomes. We are more likely to survive cancer today, which has led to reduced pessimism and fatalism about the disease.

Surviving the experience of cancer

When cancer was considered a death sentence, 'survivors' were typically family members who had survived the loss of a loved one (Lance-Armstrong-Foundation 2004). With progress in cancer detection and treatment, individuals diagnosed with cancer were deemed to have survived if they lived for five years or more disease-free (Dow 1990, Breaden 1997, Miller *et al.* 2008, Kelly *et al.* 2011). However, a more recent shift has occurred, from what Breaden (1997: 978) describes as the 'dominant metaphor of "survival as time"' to an emphasis not just on *length*, but *quality*, of survival i.e. how *well* individuals survive, and their experience of survival (Dow 1990, Zebrack 2000a, Leigh 2007, Leigh 2008, Aziz 2009). As a result, there has been movement beyond the biomedical model, which focuses on 'disease' and outcomes, to delivering treatment and care within the context of an individual's life i.e. treating the person, not just the disease – a biopsychosocial model of care (Aziz 2002, Aziz 2007). This suggests a shift in focus from *surviving the disease* to *surviving the experience* of cancer.

Dow (1990) highlighted that, unlike survivors of other life-threatening events such as natural disasters, cancer survivors continue to deal with the threat of recurrence and an uncertain future, as well as a range of late and long-term effects as a result of cancer and its treatment. The impact of these effects will affect a survivor's ability to 'thrive' (live well) after cancer (Dow 1990). In this respect, Erikson's (1976) definition of a disaster having a definitive beginning and end does not apply to cancer. In the context of a natural disaster, the term 'survivor' implies that the physical danger has passed. However, the

danger for a cancer survivor continues. In this sense, the terms 'cancer' and 'survivor' could be perceived as contradictory as 'survivor' implies 'resolution of trauma' (McKenzie and Crouch 2004) yet fails to capture the uncertainty about what the future holds post-treatment, be it the threat and fear of recurrence or living with the ongoing consequences of cancer treatment.

The cancer survivorship literature refers to the 'sword of Damocles' to highlight how the threat of recurrence hangs over cancer survivors, just as the sword was suspended over Damocles in Greek mythology (Koocher and O'Malley 1981, Frank 1995, Zebrack 2000b, Stephens 2004, Kaiser 2008). Koocher and O'Malley (1981: xvii) suggest 'the nature of cancer is that the disease may recur even after prolonged periods of apparent good health.' Individuals are treated with 'curative intent' and healthcare professionals do their utmost to reassure patients, which may lead to a sense of security and gratitude. However, concurrently, there is 'a conscious or subliminal awareness that a substantial risk, much like the sword of Damocles, hangs over their future' (1981: xviii). This, they feel, has a psychological impact on cancer survivors in terms of how they cope and adapt to life post-treatment (Koocher and O'Malley 1981). Holland (2002: 217) later said that although there are increasing numbers of survivors, they have 'psychological baggage' which may include post-traumatic distress, anxiety and sexual problems.

Therefore whilst it is clear that individuals diagnosed with cancer are surviving for longer periods, they cannot be classified as 'survivors' in the same sense as those who have experienced a life-threatening man-made or natural disaster. It could be said that, after a cancer diagnosis, individuals live in a perpetual state of survival – of both the disease itself and the experience of cancer.

Why does cancer attract the 'survivor' label?

People living after a diagnosis of cancer have survived, or continue to survive, what can be a life-threatening illness. They have done so due to better screening, and thus earlier detection, and more effective and targeted treatment. However, these treatments are themselves often toxic and dangerous and can cause debilitating side effects. Therefore, people living after a diagnosis of cancer have also survived, or are continuing to survive, the experience of cancer. Drawing on Peck's (2008) survivorship perspective, whilst a diagnosis of cancer is life-threatening, it can give way to being life-altering. This will be discussed more extensively in Chapter 3, but people diagnosed with cancer may survive an assault on their personal and social identity, life perspective and relationships, as well as coping with the threat of recurrence and facing their own mortality.

Battle metaphors prevail in discussions about cancer (Clarke and Everest 2006). We are said to battle a deadly disease, described as the enemy. Treatment plans are formulated as a 'battle plan against cancer'. Treatments themselves are portrayed with metaphors of war, such as targeted therapies. At times, the disease itself is described as 'at war' with the body or person. As such, the body itself is perceived as a battleground over cancer (Clarke and Everest 2006). Individual character is also often implicated in stories of cancer. The 'heroic' cancer fighter is described as one who 'never admitted to the disease or conceded defeat' (Clarke and Everest 2006). Therefore, cancer attracts the 'survivor' label attributed to those who have survived war, as the disease, and its treatment, are often alluded to as akin to fighting a war - and once the battle is won, the victor is worthy of the title 'survivor'. However, as will be explored further in the coming chapters, this perspective is criticised by some, including those who have 'survived' cancer, because it implies that, if someone dies, they did not fight hard enough.

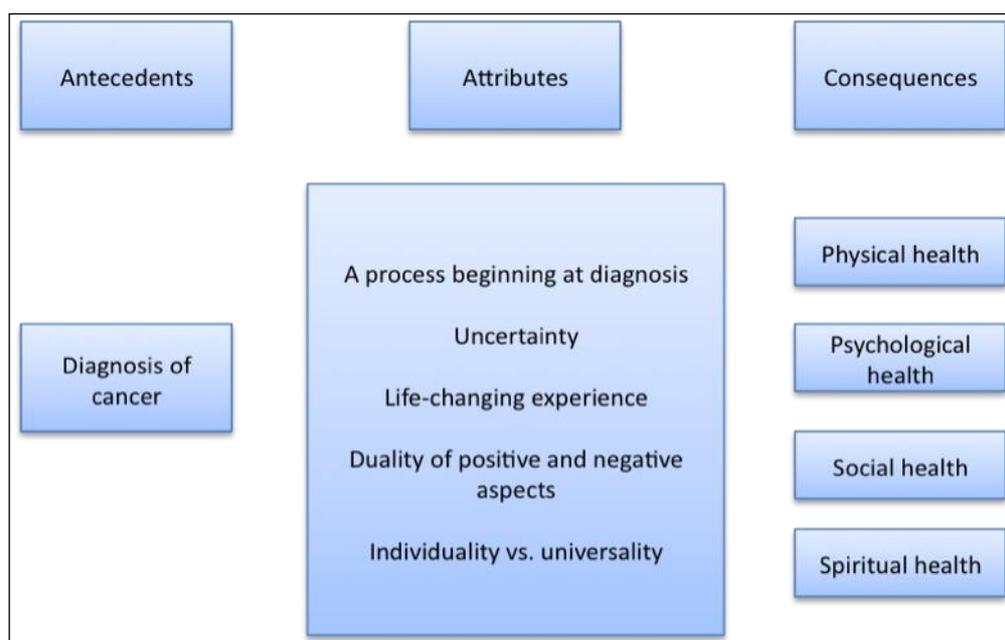
Defining a ‘cancer survivor’ and ‘cancer survivorship’ – evolution of the terminology

Studies and editorials on cancer survivorship have described the terms ‘cancer survivor’ and ‘cancer survivorship’ as evolving, undertheorised and unquestioned (Feuerstein 2007b, Feuerstein 2007a, Kaiser 2008, Foster *et al.* 2009). Often, researchers neglect to provide a definition of cancer survivor(ship), seemingly under the assumption that because the term is widely used today, its meaning is implicit. Kelly *et al.* (2011) argue that definitions used today by healthcare professionals, professional organisations, researchers and advocacy groups confuse the picture. Definitions include individuals recently diagnosed, those undergoing treatment, those who have completed treatment, those five-years post-diagnosis, as well as friends and family (Kelly *et al.* 2011). As such, the literature highlights ambiguity and confusion regarding when survivorship begins, who the term ‘cancer survivor’ refers to, who it excludes, and who it is for.

Survivorship: a process that begins at diagnosis?

As a result of its contested nature, Doyle (2008) conducted an evolutionary concept analysis of the term ‘cancer survivorship’. She identified five attributes that typify cancer survivorship (Figure 2.2). Doyle highlighted a lack of agreement as to *when* an individual becomes a ‘cancer survivor’. Essentially, there are two facets to explore: a) whether survivorship *begins at diagnosis* and b) whether survivorship is a *process*. In this section I discuss the historical evolution of the terms ‘cancer survivor’ and ‘cancer survivorship’ to explore the validity of Doyle’s assertion that survivorship is a process beginning at diagnosis.

Figure 2.2: Doyle's attributes of the concept of cancer survivorship



(Source: Doyle, 2008: 506)

The term 'cancer survivor' was adopted in 1985 by Dr Fitzhugh Mullan, a physician diagnosed with cancer, who described individuals as survivors from the point of diagnosis onwards. This was in contrast to the prevailing medical view that individuals with cancer were 'survivors' once they had lived for five years or more disease-free. Regarding his own experience, Mullan stated:

'It did not occur to me while I was acutely ill or for some time afterward that the simple concepts of sickness and cure were insufficient to describe what was happening to me... I was, in fact, surviving, struggling physically and mentally with the cancer, the therapy, and the large-scale disruption of my life. Survival was not one condition but many'

(Mullan, 1985: 271).

His seminal work described three 'seasons of survival': acute, extended and permanent, a 'generic idea that applies to everyone diagnosed as having cancer, regardless of the course of the illness' (Mullan, 1985: 271). The acute phase spans the point of diagnosis through to the completion of primary treatment. As such, the phase is dominated by tests, treatment and the management of treatment side effects (Mullan 1985). Fear and anxiety are

said to dominate this period, as people confront their own mortality. In extended survival, the survivor has to deal with the uncertainty and threat of recurrence – so-called ‘watchful waiting’ (1985: 272). They may also have to manage the long-term effects of treatment such as fatigue, altered body image, pain, role changes, etc. (Mullan 1985, Dow 1990, Pedro 2001, Kaplan 2008). As a result, it has been argued that psychosocial services are important during the extended period (Kaplan 2008). Finally, survivors enter the permanent stage. Mullan conceptualised this stage as a disease-free state ‘roughly equated with the phenomenon we usually call “cure”’ (1985: 272). Pedro (2001) suggests this stage is now referred to as long-term survival. Likelihood of recurrence is low and health promotion strategies are often adopted during this time. However, long-term consequences and the risk of late effects, such as second cancers, persist (Mullan 1985). Adjustment to life ‘beyond cancer’ is the focus of this stage (Kaplan, 2008: 989).

Mullan’s definition focuses on *surviving the experience* of cancer. His definition was adopted by the US-based National Coalition for Cancer Survivorship (NCCS) in 1986⁹. In doing so, they aimed to empower patients to take ownership of their healthcare and push for better treatment and support (Khan *et al.* 2012). The definition was subsequently adopted by the US National Cancer Institute¹⁰ and Office of Cancer Survivorship¹¹. These organisations define a cancer survivor as:

‘An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition’

⁹ The NCCS is a survivor-led advocacy organisation, campaigning for quality care and empowering cancer survivors <http://www.canceradvocacy.org/about/> [Accessed February 11th 2010].

¹⁰ The National Cancer Institute is the US Government's principal agency for cancer research and training <http://www.cancer.gov/aboutnci/overview/mission> [Accessed February 11th 2010].

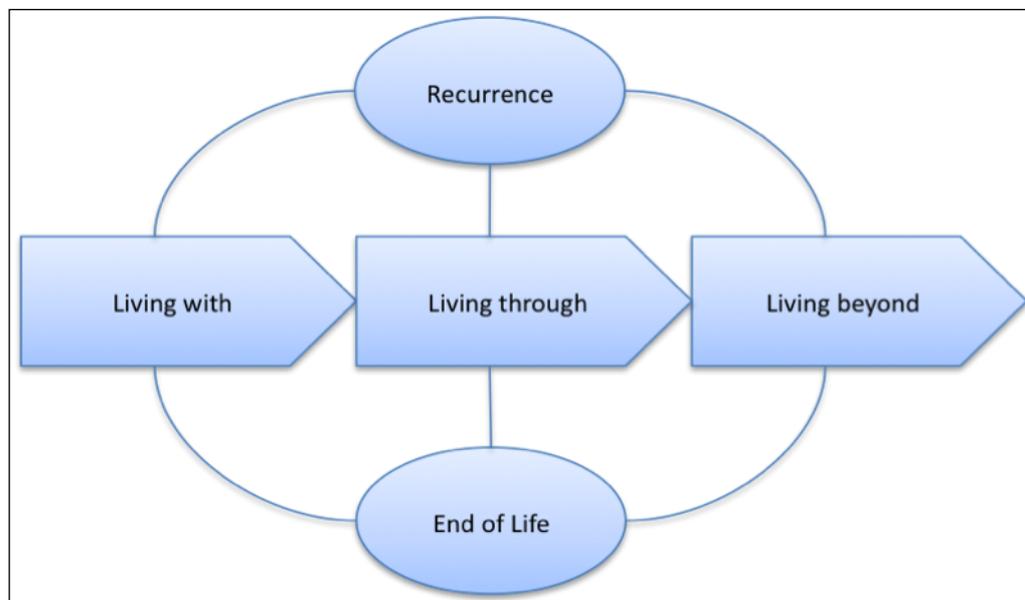
¹¹ The Office of Cancer Survivorship conducts and supports research that examines and addresses the effects of cancer and its treatment among cancer survivors and their families <http://cancercontrol.cancer.gov/ocs/about.html> [Accessed December 15th 2009].

According to Ganz (2009: 722) this was a 'bold, broad and inclusive definition, and focused attention on the large number of people affected by the patient's cancer diagnosis and survival'. However, as Table 2.3 shows, alternative conceptualisations and definitions have developed since the 1980s, some building on Mullan's work, others offering different perspectives on what constitutes 'survivorship'. For example, whilst the Lance Armstrong Foundation¹² adopts Mullan's definition of a survivor, the organisation has developed a model that sees survivors move through 'chapters' of survivorship (Figure 2.3) (Lance-Armstrong-Foundation 2004, Naus *et al.* 2009). 'Living *with* cancer' refers to diagnosis and treatment. 'Living *through* cancer' is the period from the end of active treatment through the period of time when recurrence is most likely, which many consider up to five years from diagnosis. 'Living *beyond* cancer' is five years or more post diagnosis. 'Recurrence' marks the return of the primary cancer or diagnosis of secondary disease and results in the survivor returning to 'living *with* cancer' albeit 'with altered personal characteristics and knowledge gained from the previous experience' (Naus *et al.*, 2009: 1352). The final chapter is 'End of Life' which can occur at any time but marks the time from terminal diagnosis to death (Naus *et al.* 2009).

¹² The Lance Armstrong Foundation was established in 1997 to support people through the cancer experience.

Table 2.3: Definitions of cancer survivor(ship)				
Organisation	Country	Type of organisation	Definition of cancer survivor(ship)	Comments
National Coalition for Cancer Survivorship (NCCS) (1986)	USA	Advocacy/support	Living through and beyond cancer. From diagnosis onwards. Includes 'secondary survivors' – family, friends, caregivers – to draw attention to large number of people affected by a diagnosis of cancer	Most widely accepted definition. Designed to empower
National Cancer Institute (NCI)/Office of Cancer Survivorship	USA	Government	As for NCCS. An individual is a survivor no matter when diagnosis was made or whether cancer was treated successfully	Do not include secondary survivors in statistics
Lance Armstrong Foundation (2004)	USA	Advocacy/support	From diagnosis onwards. 'Chapters of Survivorship': living with, through & beyond cancer	
American Cancer Society (ACS)	USA	Advocacy/support	People living with cancer. Survivors after treatment.	Has struggled with the term
Memorial Sloan-Kettering Cancer Centre	USA	Cancer Centre/research	Living beyond cancer. Period post-treatment, separate from diagnosis and treatment, and end of life care	Report some backlash against the term 'survivor'
Macmillan Cancer Support (and National Cancer Survivorship Initiative), Department of Health	UK	Advocacy/support/ Government	Living with, and beyond, cancer. Includes individuals who: have completed initial treatment and are disease-free, are living with progressive disease and may be receiving treatment, but the disease is not at the terminal stage or have had cancer in the past	
Author(s)		Background		
Mullan (1985)	USA	HCP, Cancer survivor	Survivor from diagnosis onwards, 3 seasons of survival: acute, extended and permanent	Family referred to as 'secondary patients'
Feuerstein (2007a, 2007b)	USA	Cancer Survivor, Research	Phases of survivorship: diagnosis, treatment, acute, sub-acute, chronic; end of life. Journal of Cancer Survivorship: Adults with a cancer diagnosis, who have completed primary treatment until end of life.	
Doyle (2008)	UK	HCP, Research	Cancer survivorship has 5 attributes: a process beginning at diagnosis, involves uncertainty, life changing experience, positive and negative aspects and individuality vs. universality	
Miller <i>et al.</i> (2008)	USA	HCP	Seasons of survival 'revisited': acute, transitional, extended and permanent	Does not include family. But caregivers referred to as 'the other cancer survivors' with their own challenges

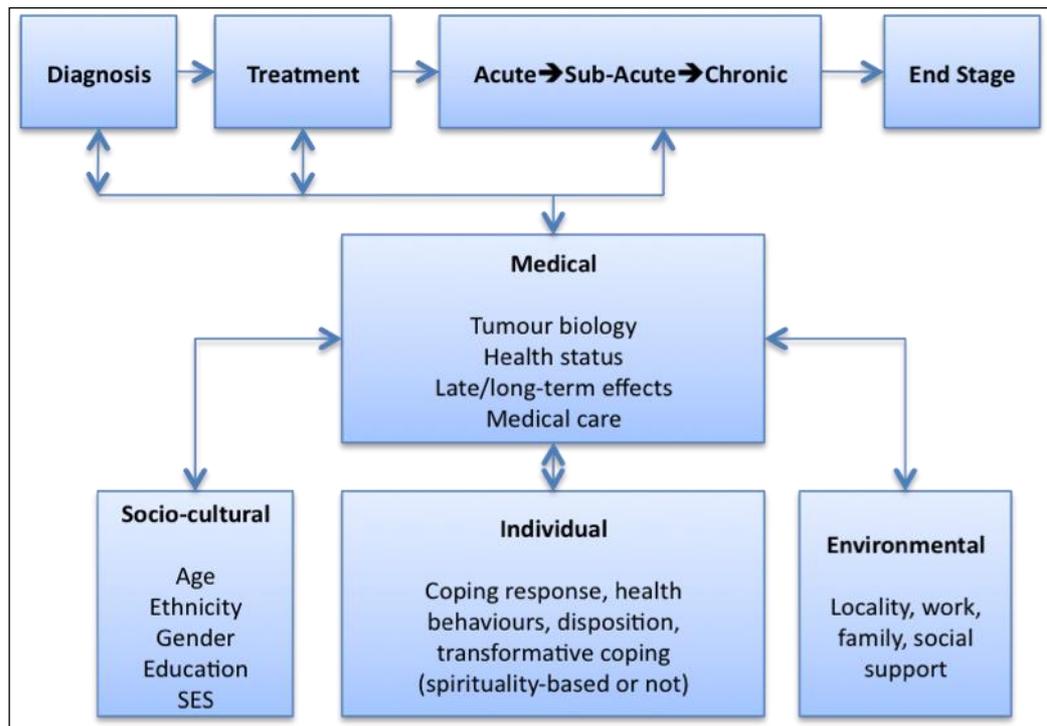
Figure 2.3: Lance Armstrong Foundation ‘chapters’ of cancer survivorship



(Sources: Lance Armstrong Foundation, 2004; Naus *et al.*, 2009)

Feuerstein (2007a: 484) argued that previous definitions put forward by the likes of Mullan were useful but ‘more realistic operational definitions of survivorship’ were needed. As a result, he developed a stage-based conceptual framework, which included six phases: diagnosis, treatment, acute, sub-acute, chronic (long-term) and end stage (Figure 2.4). Acute and sub-acute in Feuerstein’s model refer to the period following primary treatment. Survivors can move forward and backward through the stages, and various factors can impact the cancer experience in each phase. Feuerstein developed the model to help ‘organise research and thinking in the area’ (2007a: 489), hence his focus on operational definitions of survivorship from which research can be designed. For Feuerstein, like Mullan, survivorship begins at diagnosis. However, unlike Mullan (and therefore the NCCS and NCI), Feuerstein does not include family in his definition, although he acknowledges the importance of family and wider support systems in survivorship.

Figure 2.4: Feuerstein's 'phases' of survivorship



(Source: Feuerstein, 2007a: 489)

An alternative definition of a 'cancer survivor' as an individual who has finished primary treatment has also been adopted. For example, Macmillan Cancer Support, a UK-based cancer charity, describes cancer survivors as those 'living with, and beyond, cancer'. The organisation's definition includes individuals who have completed initial treatment and are disease-free; those living with active disease who may be receiving treatment, but the disease is not terminal; or those who have had cancer in the past. The National Cancer Survivorship Initiative (NCSI) adopts the same definition, focusing its efforts on understanding cancer survivors' needs and developing models of care that will allow individuals to return to healthy and active lives following the completion of treatment (Richards *et al.* 2011). Khan *et al.* (2012) suggest this definition has been adopted by policy makers in the UK to enable them to target services to this specific population.

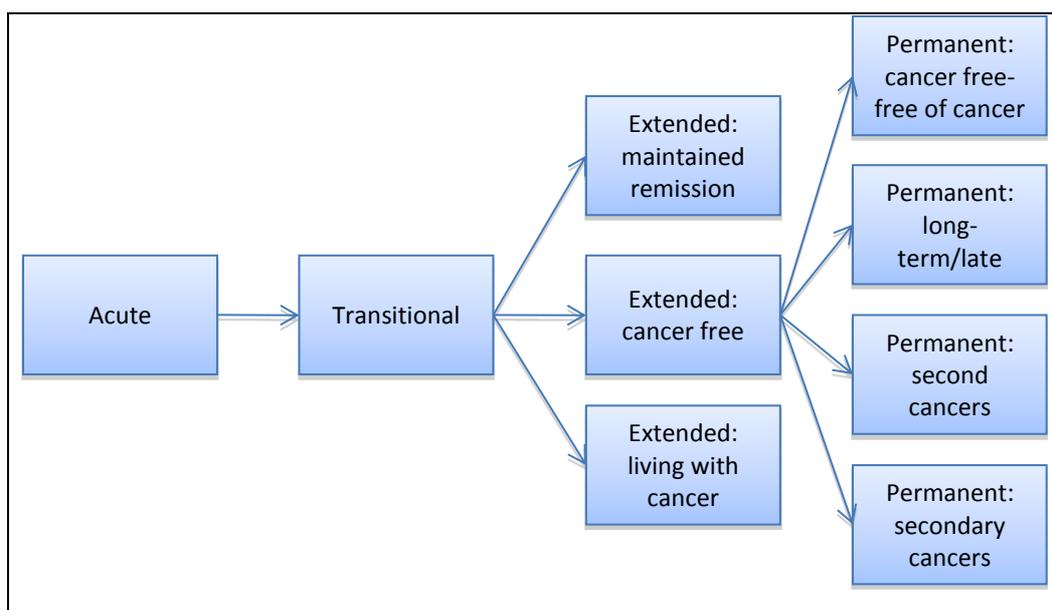
Several researchers have gone on to distinguish between 'disease-free' survivors and those 'living with cancer' i.e. those still being treated for cancer (recurrence or metastatic disease) (Griffiths *et al.* 2007, Miller *et al.* 2008,

Phillips and Currow 2010) rather than include them under one banner of 'cancer survivors' or 'living with, and beyond, cancer'. In their study of the ongoing needs of survivors of rarer cancers, Griffiths *et al.* (2007) described the entire sample as survivors but categorised them further into those who were disease-free, had a good prognosis but might suffer a recurrence (disease-free survivors) and those who were living with disease and would at some stage die from that cancer (living with cancer). Conceptually these distinctions are helpful as they allow the differing needs and experiences of these sub-groups of survivors to be identified and explored. These ideas were developed further by Miller *et al.* (2008) who 'revisited' Mullan's seasons of survival to reflect changes seen in cancer survivorship since Mullan's (1985) seminal paper.

Miller *et al.* (2008) argued that Mullan's 'seasons' are more complex than originally defined. They suggested a new phase ('transitional survivorship'), and developed the extended and permanent phases (Figure 2.5). Transitional survivorship refers to the period following completion of primary treatment. It is 'the difficult time when celebration is blended with worry and loss as a patient pulls away from the treatment team' (Miller *et al.*, 2008: 372). In this phase, survivors enter a period of 'watchful waiting' (2008: 372), as the risk of recurrence is greatest. Miller *et al.* (2008) felt that the issues and concerns experienced at this time warranted a separate phase.

Miller *et al.* (2008) also provided a more detailed breakdown of the 'extended' survivorship period, suggesting three subgroups of survivors in this phase. The first group are those in remission, and not receiving further treatment (cancer free). The second are also in remission but receiving ongoing therapy (maintained remission), and the final group are those with advanced disease, who are undergoing treatment (living with cancer). Miller *et al.* developed sub-categories within extended survivorship due to heterogeneity in the needs of survivors within these groups.

Figure 2.5: Miller *et al.*'s 'seasons of survivorship'



(Source: Miller *et al.*, 2008: 371)

Miller *et al.* (2008) also developed Mullan's season of 'permanent' survival. This phase embodies 'a gradual sense or confidence that the risk of recurrence is low and that the chance of long-term survival is great' (Miller *et al.*, 2008: 372). They proposed four groups: cancer free-free of cancer, cancer-free but not free of cancer, secondary cancers and second cancers. The first group is in remission and has experienced little 'fall-out' (physical or emotional impact) as a result of cancer. Cancer is said to be part of the past. For the second group, they too are in remission but they experience 'fall-out' from the disease (long-term and/or late effects of cancer and its treatment). The third and fourth groups are still classified as survivors but they have either developed a second primary cancer or the disease has metastasised.

The permanent survival stage (Mullan 1985, Miller *et al.* 2008) is sometimes referred to as long-term survivorship, a concept also discussed extensively in the literature. Historically, survivors have been defined as such when they reach five years post-diagnosis. However, increasingly this group are referred to as 'long-term survivors' (Carter 1993, Gotay and Muraoka 1998, Pedro 2001, Aziz 2002, Vivar and McQueen 2005, Sugimura and Yang 2006, Aziz

2007, Bloom *et al.* 2007, Davies 2009, Foster *et al.* 2009). Yet, as with the definition of cancer survivorship itself, there continues to be confusion and debate as to how to define 'long-term' survivorship (Vivar and McQueen 2005). Some commentators suggest Mullan's permanent survivorship phase corresponds to three years or more post-diagnosis (Bloom 2002, Hodgkinson *et al.* 2007). However, as shown above, others argue that long-term survivorship begins five years or more post-diagnosis. Defining permanent survivorship as five years post-diagnosis corresponds with the Lance Armstrong Foundation's 'chapter' of 'living beyond cancer'.

Summary - evolution of terminology

The term 'cancer survivor' was coined in the mid-1980s by Fitzhugh Mullan, a doctor who had himself been diagnosed with cancer. Mullan did not feel that the focus on 'cure' (or the disease) reflected the experience of being diagnosed with cancer, for example, the effect of treatments, existential concerns, etc. - in other words, the life-altering aspects of the disease. His purpose in coining the term 'cancer survivor' was to help people take control of their treatment and care, and be more vocal and involved in the decisions which would impact their future health and wellbeing. He wanted to empower people diagnosed with cancer at a time when they may feel powerless.

Around the same time, the media portrayal of cancer was beginning to influence the way society perceived those diagnosed with cancer, as well as the rhetoric used to describe and define them. It was only in the 1970s that doctors began telling patients that they had cancer, which resulted in people being more open about the disease, in particular, their feelings and experiences of being diagnosed with a life-threatening illness (Holland 2002). Holland highlights that this development coincided with significant social changes, namely greater optimism about cancer due to improving survival

rates and treatments, and celebrities talking about their cancer experiences. Through the development of new treatments, improving survival rates and people being more willing to discuss their cancer experiences, the perception of cancer shifted from that of a secretive, stigmatised death sentence to a disease some 'survivors' feel proud to have overcome and openly share their experiences, their stories often being used for advocacy purposes. As Holland (2002: 213) put it 'cancer came out of the closet'.

However, as survival outcomes continue to improve, the term 'cancer survivor' has also been adopted by policy makers and researchers, in part, to delineate the population so it can be counted. Today, this is an increasingly important consideration because more people are surviving cancer, and for longer. Therefore, services need to be planned, research commissioned and policies developed to ensure the needs of those affected by cancer are met. However, as has been alluded to, different definitions of a 'cancer survivor' are used in different contexts and for different purposes. The next section explores how the term 'cancer survivor' has been appropriated.

How, and by whom, the term 'cancer survivor' has been appropriated

The definition of a 'cancer survivor' will depend on the purpose for which the terminology is being used, for example, advocacy, research, policy, service delivery, etc. This section explores the different contexts within which the term is appropriated.

Cancer advocacy

For some, the overall goal of cancer survivorship continues to be to empower survivors and their families (Morgan 2009). The term 'survivor' suggests 'activated patients' (Beckjord *et al.* 2008) who interact with the healthcare

system proactively. In England, patient empowerment is key to the success of the NCSI's Vision of 'aftercare' as it relies on survivors taking a participatory role in maintaining their health and wellbeing.

Some cancer survivors choose to act as self-advocates, advocates for others with cancer or chose to join public advocacy movements. According to Zebrack (2001) defining oneself as a cancer survivor can empower them to act – find information, engage in decision-making and facilitate coping. Additionally, it can be an empowering experience to give something back, sharing experiences with others who have been through something similar (Zebrack 2001). Advocacy efforts since the 1980s have led to the survivorship agenda 'gaining momentum' (Leigh, 2007: 12). Leigh refers to the development of a 'critical mass' which means that the issue of cancer survivorship can no longer be ignored (Leigh 2007). Leigh suggests that advocates have created a new social 'movement' by combining the words 'cancer' and 'survivorship' (Leigh 1994, Leigh 2008). As Leigh puts it 'consumer advocates no longer could be ignored as they organised, networked, marched, and raised their collective voices to be part of health care debates' (Leigh, 2008: 246). Higher expectations of surviving cancer, alongside increased access to information, have fuelled the cancer survivorship movement (Leigh 1994) and shift in mindset from viewing a person affected by cancer as a 'powerless victim' to an 'empowered survivor' (Leigh, 1994: 783). According to Leigh, defining themselves was in itself an act of empowerment.

Zebrack (2001) highlights the development of a cancer survivorship 'movement' whereby cancer survivors have played a key role in the development of cancer support and advocacy organisations. He talks of a 'new breed of cancer survivor' who volunteer, take part in research projects, raise funds, organise community forums, form cancer support groups and networks (Zebrack, 2001: 286). For some the term could be used to celebrate the changing picture of cancer: that more people are surviving cancer and for longer. Survivors also influence government policy. It is argued that the NCCS

was instrumental in the establishment of the Office of Cancer Survivorship at the US National Cancer Institute in 1996 (Hoffman and Stovall 2006). Therefore Mullan's definition of a survivor as someone from the point of diagnosis onwards took the emphasis away from 'relying solely on the agendas of the healthcare community' (Leigh, 1994: 783) which has traditionally focused on disease outcomes i.e. survival rates.

'Secondary survivors'

Twombly (2004) refers to 'secondary survivors' who include family, friends, caregivers and colleagues. They have often gone through the cancer experience with the person diagnosed. Dow (1990: 513) argues 'the experience of surviving is also a shared one within families. This points to the need for inclusion of family members in the process of surviving and determining their meaning of surviving the illness'. They too could be said to have 'survived' the shock of diagnosis, the side effects of treatment and the uncertainty of life post-treatment. However, referring to them as 'secondary survivors' highlights that they have not gone through the same physical, emotional, social and spiritual experience as the person diagnosed with cancer, and thus suggests that they should not be labelled in the same way.

The term 'cancer survivor' may help these 'secondary survivors' come to terms with the fact that someone close to them has been diagnosed and treated for a life-threatening illness. Research, explored in greater depth in Chapter 3, highlights that there is a socially acceptable way for cancer survivors to act post-treatment (Little *et al.* 1998, Little *et al.* 2002, Little 2004, Little and Sayers 2004b, McKenzie and Crouch 2004). Kaiser discusses the 'language of survivorship', how cancer survivors are expected to 'fight the good fight', battle the disease, wage a war on cancer whilst maintaining a positive outlook (Kaiser, 2008: 81). Not only is this thought to benefit the cancer survivor in terms of positive adjustment and quality of life post-

treatment but it also helps family and friends feel less anxious and concerned about not just the cancer survivor's future, but also their own.

So, in this sense, the term 'survivor' is as much for family and friends as it is for the cancer survivor. Problems arise, however, if cancer survivors find it difficult or impossible to maintain such a positive outlook or seek to find meaning from the experience (Little *et al.* 2002, Little and Sayers 2004b, McKenzie and Crouch 2004, Kaiser 2008). This can lead to unwelcome feelings on the part of 'secondary survivors'. A 'mismatch' of emotions and future plans can lead to 'social distancing' in close relationships (McKenzie and Crouch, 2004: 143).

The impact of cancer on relationships, as well as the experience of survivorship from the perspective of both the survivor and their significant others will be explored further in Part 2 of the literature review and in the analysis.

Healthcare professionals

Traditionally, the medical community defined a someone as a 'cancer survivor' if they had been disease-free for five or more years (Mullan 1985, Dow 1990, Hodgkinson *et al.* 2007, Miller *et al.* 2008). The five-year marker is a) in reference to survival statistics; b) clinically relevant as individuals are at a lower risk of recurrence and c) the point when clinical follow-up typically stops. Breaden (1997) refers to this as 'survival as time' (1997: 978). Therefore healthcare professionals tend to describe survivorship in a biomedical sense. 'Survival as time' is useful for quantitative analysis but 'only tells part of the story' (Stephens, 2004: 30). It does not describe the meaning people give to their illness or how they cope post-treatment (Wallwork and Richardson 1994, Breaden 1997, Stephens 2004). Kleinman (1988), himself a healthcare professional, advocated listening to patient stories, to understand their illness

experience and incorporate this understanding into clinical practice – a biopsychosocial model of care. With this in mind, even if clinicians define someone as a ‘survivor’ as someone who has been disease-free for five years, discussions about, and planning for, the ‘survivorship’ period, should begin during the diagnosis and treatment phase of the cancer trajectory. This is to ensure that the treatment plan, and potential side effects of treatment, are considered within the context of the patient’s wider life story. Issues to consider include what impact treatment might have on the patient’s ability to live a healthy and active life, and what information and support that patient might need to do so, post-treatment.

Policy makers

In 2007, the Department of Health launched the Cancer Reform Strategy, which set a clear direction for cancer services in England (Department-of-Health 2007). The Strategy included a chapter on ‘Living with and beyond cancer’ which, in light of the increasing number of cancer survivors in England, highlighted the importance of identifying the information, support and service needs of cancer survivors. To support the survivorship agenda in England, the National Cancer Survivorship Initiative (NCSI) was established in 2008. The aim of the NCSI is to ensure survivors get the care and support they need to lead healthy and active lives, for as long as possible. This mirrors the goal of the US Office of Cancer Survivorship, which is ‘to focus on the health and life of a person with a history of cancer beyond the acute diagnosis and treatment phase’ (Aziz 2007). Therefore, the policy focus appears to be on what happens to people once they have completed treatment. One of the most pressing issues was that, until relatively recently, we did not know how many ‘cancer survivors’ there were. It was only in 2009 that figures on the number of ‘cancer survivors’ (people living after a cancer diagnosis) were published in the UK (Maddams *et al.* 2009). Only then could policy makers, alongside clinicians, researchers and ‘cancer survivors’ themselves, begin to plan the

'aftercare' for cancer survivors to ensure their ongoing health and wellbeing post-treatment. However, clarity of definition is vital when presenting figures on the number of 'cancer survivors'. For example, the US Office of Cancer Survivorship includes family in their definition of a 'cancer survivor' but does not include them in statistics.

The research community

Various definitions of 'cancer survivor' are used by researchers and, on occasion, not consistently within the same research projects! For example, a five-year longitudinal project funded by the US National Cancer Institute on long-term cancer survivors produced several papers (Bowman *et al.* 2003, Deimling *et al.* 2006b). There are inconsistencies in the papers regarding the definition of a 'long-term' cancer survivor. In one paper it was five years or more *post-diagnosis* (Deimling *et al.* 2006b) yet in another it was five years or more *post-treatment* (Bowman *et al.* 2003). In the Bowman *et al.* (2003) study one of the variables used in statistical modelling was 'years of survivorship' (a self-reported measure of current age minus age at diagnosis) which does not correspond to their definition of long-term survivorship as five years or more post-treatment. This example demonstrates the importance of clarity and consistency in terms used. A multitude of definitions makes comparison of findings across studies problematic.

Does the term 'cancer survivor' resonate with those to whom it applies?

Despite the widespread use of the term today, not all so-called 'cancer survivors' are happy with the label bestowed upon them. Indeed, Leigh (2008: 248) suggests that many survivors 'loathe' the term. Twombly (2004) highlighted that patient organisations in the USA, such as the American Cancer Society and National Breast Cancer Coalition (NBCC), are not

necessarily happy using the term as it 'can be used to suggest more success in winning the war on cancer than is warranted' (Twombly, 2004: 1415). Taking breast cancer survivors as an example, the NBCC President, Fran Visco, said that defining a breast cancer survivor as such 'paints more of a pretty picture of breast cancer than exists' and that 'there is a lot of contention among women with breast cancer about what label we should use' (Visco cited in Twombly, 2004: 1415). The label does not sit well with many due to the fact that life after a cancer diagnosis can be challenging. People live with the life-altering effects of the disease and its treatment. The 'cancer survivor' label may make some people feel inferior, or that they have failed in some way, People may not feel they can call themselves a 'survivor' if they do not fit the profile of a 'cancer survivor': someone fit and healthy, volunteering, helping others, fundraising, etc.

Kaiser (2008) suggests that the survivor identity does not reflect the experience of women with breast cancer. She argues that there is a danger that public perception, often fuelled by the media, can have a negative effect on women (Kaiser 2008). Individuals are expected to approach their cancer with a positive attitude - to be happy, healthy, feminine and return to fulfilling lives and roles. Women are discouraged from showing the physical impact of their treatment, and encouraged to bury their emotions. The impact of 'pretending to be well' can be life-changing, as women who disguise their suffering may suffer emotionally as a result (Kaiser, 2008: 81). Kaiser found that, despite the positive connotations implied by the label 'cancer survivor', some women actively rejected the label as they did not want to be defined by their illness. She also found that it alienated women who a) struggled with the threat of recurrence and thus did not feel that they had actually 'survived', b) felt that cancer had not been that severe and therefore did not warrant the survivor identity or c) desired a 'private disease experience' (Kaiser, 2008: 79).

Pressure is placed on people living after a cancer diagnosis to project a positive image. In Western culture, an individual cannot be seen to be a victim

once the perceived 'sick role' is over. As such, the term 'cancer survivor' was designed to be an empowering concept. But what if an individual affected by cancer cannot, or does not, feel like a survivor due to any number of physical, psychological or social consequences experienced as a result of cancer and its treatment? Kaiser found that some women actively 'crafted' new illness labels in response to their rejection of the 'survivor' identity (Kaiser, 2008: 86).

Alternative labels reported in the literature include: 'people living with cancer' (American Cancer Society), 'post-treatment survivors' (Meneses *et al.* 2007, Jefford *et al.* 2008), 'co-existing with cancer' (Kaiser 2008), 'warriors' (Kaiser 2008), 'thrivers' (Dow 1990, Bloom 2002), 'cancer post-patients' (McKenzie and Crouch 2004), 'living with cancer' (Macmillan Cancer Support), 'living beyond cancer' (Memorial Sloan Kettering Cancer Center) and 'living with, through and beyond cancer' (Leigh and Logan 1991, Leigh 1994, Leigh 2008). A minority prefer to be referred to as 'victims' (Twombly 2004, Park *et al.* 2009) or 'sufferers' (Leigh 2008). A recent UK-based study suggested that we consider using 'descriptive terms' to describe this population, such as 'people who were diagnosed with cancer five years ago' (Khan *et al.*, 2012: 184). A more in-depth account of perceptions of the 'survivor' label and whether individuals adopt the 'survivor' identity are explored further in Chapters 3, 7, 9 and 10.

Use of the terms 'cancer survivor' and 'cancer survivorship' is common place today, despite some 'backlash' by those to whom the label refers. As Khan *et al.* (2012) have stated with respect to the NCSI, new pathways of aftercare have been developed using a label and definition of a 'cancer survivor' that does not always resonate with the population it aims to support. As shall be discussed further in this thesis, people living after a cancer diagnosis may not identify with the terminology used to define them and, consequently, may not use services that have been designed to support them because they do not think they are relevant.

Summary

With improved screening, and thus earlier detection, along with more effective treatments, cancer survival rates continue to improve. More people are surviving cancer, and for longer, which has led to the increasing adoption of the term 'cancer survivor'. Whilst people can survive cancer today, this is sometimes at a cost to the individual and those close to them. Cancer and its treatment can affect physical, psychological and social functioning. As a result, the disease can be life-altering as well as life-threatening. Therefore, on the one hand, cancer survivorship focuses on treating the disease and emphasises *length* of survival. However, more recently, there has been a shift in emphasis to focusing on the *quality* of survival and how an individual survives the illness experience, as well as the disease itself.

Kaiser rightly describes the term 'cancer survivor' as 'ubiquitous' (2008: 79). Various definitions are used by clinicians, researchers, policy makers and advocacy organisations. Yet, it is for this very reason that the term has become confused and contested. Whereas the term was originally meant to empower patients to become actively involved in their healthcare, it has now been adopted by researchers, clinicians and policy makers as a way to categorise this population so they can be counted and studied. As a result, there is debate regarding *who* is a 'cancer survivor', *when* someone becomes a 'cancer survivor' and whether the term even resonates with those to whom it refers.

Doyle (2008) has argued that survivorship is a *process that begins at diagnosis*. The literature clearly supports the conceptualisation of survivorship as a process. Indeed, models developed by Mullan (1985), The Lance Armstrong Foundation (2004), Feuerstein (2007a; 2007b) and Miller *et al.* (2008) demonstrate how survivors move through various stages or transition points along a survivorship trajectory. However, the idea that survivorship begins at diagnosis is contested. The crux of the debate rests on whether an

individual is a cancer survivor from the point of diagnosis, or on treatment completion, and consensus is yet to be reached. What we can say is that a diagnosis of cancer initiates a survivorship trajectory, which is specific to the individual and persists for the rest of their life (Zebrack 2000a). Zebrack (2000a: 239) describes survivorship as a 'continual, dynamic and ever-changing process' also defined as 'the experience of living with, through, or beyond cancer'. At the very least, discussions about survivorship care should begin at diagnosis because issues that may arise post-treatment, such as long-term and late effects of treatment, should be planned for during the acute phase of the trajectory: 'survivorship care...commences at diagnosis and continues throughout the survivor's life in order to optimise their outcomes' (Phillips and Currow, 2010: 50).

Study definitions

For the purposes of clarity, Khan *et al.* (2012) argue that context-specific 'operational definitions' of a 'cancer survivor' should be employed. Indeed, Leigh (2008: 248) suggests that 'the easiest way to deal with the controversy is to define the terms depending on the program, project, or population being served'. Therefore, based on this literature review, I have developed definitions of a 'cancer survivor' and 'cancer survivorship' to enable me to define the population to be studied. I make the distinction between the terms 'survivor' and 'survivorship' to provide clarity in use of terminology. The definitions presented here are done so whilst acknowledging that not all participants will identify, or define, themselves in the same way.

Cancer survivor: an adult diagnosed with cancer who has finished primary treatment. A broad definition such as this is not always helpful as it does not account for the differing needs and experiences of those who have completed treatment. Therefore, 'survivors' can be classified as:

1) **Disease-free**¹³ (they have a good prognosis, but live with the possibility of recurrence. They may also be undergoing treatment to reduce the risk of recurrence) or,

2) **Living with active disease** (living with, and being treated for a recurrence, second primary cancer or metastatic disease. They are not in the terminal stages of illness)

Based on the work of Miller *et al.* (2008) disease-free cancer survivors can be further categorised:

- Cancer free-free of cancer (little ‘fall-out’ from cancer and its treatment)
- Cancer free-not free of cancer (experience ‘fall-out’ from cancer such as late and long-term effects of treatment)

Cancer survivorship: The term ‘survivorship’ is used in various contexts. It is a **phase** of the cancer trajectory, which begins post-treatment. The term ‘survivorship’ has been appropriated by policymakers, clinicians and researchers to delineate a broad trajectory that ‘survivors’ follow. Whilst the trajectory is specific to the individual, it is said to include transitional, extended and long-term phases (Figure 2.6).

- **Transitional survivorship** (*end of treatment to c. 2 years post-treatment*)

This is a period of ‘watchful waiting’, where risk of recurrence is greatest. ‘Survivors’ experience fear of recurrence and uncertainty, whilst attempting to ‘re-enter’ “normal” life. Some may experience long-term effects of treatment.

¹³ Disease-free refers to free of cancer. Participants may have co-morbidities that existed prior to cancer, or developed subsequently, possibly as a consequence of cancer treatment.

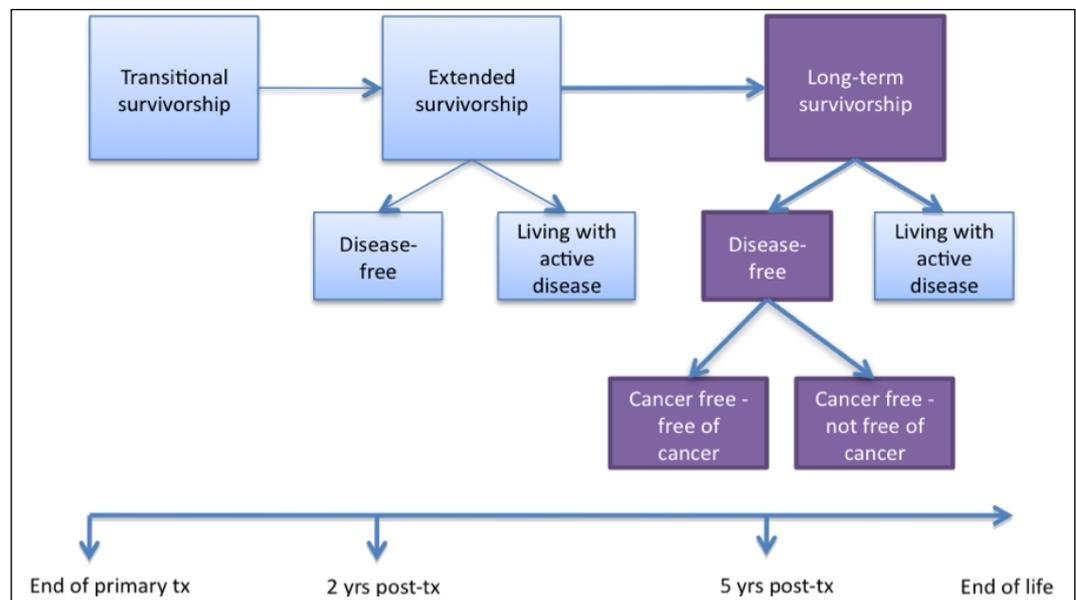
- **Extended survivorship** (c. 2-5 years post-treatment)

‘Survivors’ may continue to experience late and long-term effects of cancer and its treatment, but the risk of recurrence is reduced. Health promotion and lifestyle changes are sometimes adopted¹⁴.

- **Long-term survivorship** (c. 5+ years post-treatment)

The cancer experience may be incorporated into daily life. ‘Survivors’ are adjusting to a ‘new normal’, focusing on other aspects of living. Risk of recurrence is low, but ‘survivors’ may still experience late and long-term effects of treatment. Health promotion activities continue¹⁵.

Figure 2.6: Cancer survivorship model used in the study



Feuerstein (2007b) suggests it is preferable to provide data on the duration of time since treatment completion, rather than diagnosis, due to differing treatment lengths. Therefore the length of each survivorship phase in my

¹⁴ What the Lance Armstrong Foundation (2004) refers to as ‘living through’ cancer.

¹⁵ What the Lance Armstrong Foundation (2004) refers to as ‘living beyond’ cancer.

model is measured by time since treatment completion. This also reflects the definition of a 'cancer survivor' to be used in the study. Timescales are likely to vary from individual to individual but those presented in Figure 2.6 reflect the work of Feuerstein (2006, 2007) and Miller *et al.* (2008). It is beyond the scope of this thesis to explore the salience of these phases to the individual, or the timescales of movement from one stage to another.

Whilst I define a 'cancer survivor' as an individual who has completed primary treatment, 'survivorship' is also a **process** that begins at diagnosis. This is because issues and concerns that may arise post-treatment should be considered during the acute phase of diagnosis and treatment. As such, 'survivorship' also focuses on the **experience of being a 'survivor'**. This definition has been adopted by advocacy organisations through which a survivorship 'movement' has been established, which aims to empower patients to push for better treatment and care.

Conclusions and next steps

As mentioned in the Introduction (Chapter 1), there are nearly fourteen million cancer survivors in the USA (American-Cancer-Society 2012). Sixty-four percent of these were diagnosed over five years ago. There are approximately two million cancer survivors in the UK. Of these, 1.24 million were diagnosed more than five years ago (Maddams *et al.* 2009)¹⁶. These statistics support Leigh's (2008) assertion that the population generating the most debate and needing most attention is long-term cancer survivors. Therefore, this study is interested in exploring the experience of disease-free individuals in the long-term survivorship phase (≥ 5 years post-treatment). Chapter 3 seeks to further justify the study's focus on long-term survivorship and critically synthesises existing research on experiences during this phase of the cancer trajectory.

¹⁶ Those living with a diagnosis of cancer at some point in their past (Maddams *et al.*, 2009).

Chapter 3. Literature Review: Part 2 - The experience of long-term cancer survivorship

Introduction

The second part of the literature review seeks to justify the study's focus on long-term cancer survivorship, and synthesises literature on the experience of survivorship during this phase of the cancer trajectory.

The majority of studies on cancer survivorship focus on 'quality of life' issues (Harrop *et al.* 2011). 'Quality of life' is a multi-dimensional construct that encompasses four domains: physical, psychological, social and spiritual functioning (Ferrell *et al.* 1995, Bloom *et al.* 2007). Research on quality of life looks beyond *length* of survival to *how well* people are surviving (Jacobsen and Jim 2011). However, quality of life studies tend to adopt a biomedical model, which focuses on outcomes, collecting statistical data on 'problems' experienced by cancer patients, such as depression and anxiety. Studies aim to *explain* these problems. Therefore, whilst data exist documenting psychosocial difficulties, discussion of the meaning of these difficulties within their wider socio-cultural context, particularly for long-term survivors, is still rare (Loescher *et al.* 1990, Tomich and Helgeson 2002). As such, there are calls to move beyond the 'distress' focus in psychosocial oncology towards a biopsychosocial model, which aims to *understand* the illness experience (Mathieson and Stam 1995, Costain Schou and Hewison 1999).

Like Costain Schou and Hewison (1999), Hubbard and Forbat (2012) argue that survivorship research has thus far demonstrated a 'dislocation of psychosocial impacts of the disease from the social context' (2012: 2034). However, they go on to state that there is a 'rich seam of research that has addressed some of these limitations exploring how people make sense of

their illness in the context of their lives' (2012: 2034). This includes focusing on the 'nitty-gritty' aspects of life (Costain Schou and Hewison 1999), exploring how cancer is experienced day-to-day, the meaning survivors ascribe to their illness, and the impact of cancer on one's self-concept, outlook on life and relationships. Construction of meaning is a 'social process' achieved through interaction with others, and within specific local contexts (Costain Schou and Hewison 1999). As such, the importance of looking at micro (interpersonal relationships) and macro (wider societal) factors in understanding how illness is 'lived' day-to-day is emphasised (Anderton *et al.*, 1989 in Lawton, 2003). The review presented here aims to synthesise the small body of research that exists on the subjective illness experience and seeks to highlight methodological limitations and avenues for future research.

Design of the review

A narrative review was undertaken to provide a comprehensive overview of the experience of long-term cancer survivorship. Specifically, a thematic synthesis of findings is presented, whereby findings are organised by descriptive theme.

Search strategy

Electronic searches of PsycInfo, ASSIA, Web of Science, The Cochrane Library, CINAHL, Medline, British Nursing Index and British Library online databases were conducted in November 2009, and subsequently updated in February 2012. Search terms were generated through initial reading of seminal sociology of illness papers and reviewing key words in relevant papers. Search terms were: cancer survivor* AND experience, meaning, narrative, identity, relation*, interpersonal, communication, spiritual*, coping; and living with cancer. Databases were searched for literature in English, from 1985 onwards,

as per Part 1 of the review. In addition, lists of references from relevant papers were searched to identify articles that may have been missed during database searches. Alerts were also set up with selected online databases to inform me when new 'experience' research was published.

Inclusion and exclusion criteria

Due to the striking lack of consistency in defining (long-term) cancer survivorship, it was a challenge deciding which papers to include for review. As Bellury *et al.* (2011) state 'one of the difficulties of synthesizing survivorship research is that over the years time frames for defining survivorship have varied' (2011: 237). If papers focusing solely on those living more than five years post-treatment were included (as per my definition of a long-term survivor), an important contribution to our understanding of the cancer experience would be lost. Therefore, papers covering a range of survivorship phases, but including long-term survivorship, have been reviewed. Papers have been excluded if the sample included only those from diagnosis up to five years post-treatment.

Papers were included if they:

- Focused on individuals diagnosed in adulthood (≥ 18 years old)
- Included individuals five years or more post-diagnosis or treatment
- Included survivors from across the disease trajectory (i.e. acute survivorship onwards) but mean time since diagnosis/treatment was ≥ 5 years
- Focused on the subjective illness experience

Papers were excluded if they:

- Focused solely on childhood/adolescent cancer survivors, or adult cancer survivors diagnosed in childhood
- Focused on experiences of cancer recurrence or metastatic disease

- Included samples of survivors solely in the acute, transitional or extended survivorship phases, or if mean time since diagnosis/treatment was ≤ 5 years
- Focused solely on quality of life i.e. measuring and/or predicting psychosocial outcome measures
- Focused solely on the experiences of, or impact on, 'significant others'

Search outcome

The search yielded forty-three papers on the experience of long-term cancer survivorship (Table 3.1). Of these, twenty-six were specifically on survivors five years or more post-diagnosis/treatment. Table 3.2 outlines the papers included for review, presented according to the main focus of the paper. Additional themes in the papers are also highlighted. Key themes were: searching for meaning in the cancer experience; the impact of cancer on self and outlook on life; and the impact of cancer on interpersonal relationships.

Table 3.1: Main focus, and number, of papers identified during the literature search

Main focus of paper	Papers including LTCS ¹⁷	Papers specifically on LTCS ¹⁸
Searching for meaning	27	18
Self and outlook	12	7
Interpersonal relationships	4	1
Total	43	26

It should be noted that there was substantial cross-over between themes. For example, positive changes to self are a facet of post-traumatic growth, which falls within the 'searching for meaning' theme. As such, papers often

¹⁷ Mean time since diagnosis/treatment is ≥ 5 years, but the sample may include survivors < 5 years post-diagnosis/treatment.

¹⁸ Where the whole sample is ≥ 5 years post-diagnosis/treatment.

Table 3.2: 'Experience' papers included for review									
Author(s)	Year	Country	Cancer-type(s)	Methods	Specified theoretical framework	Main focus of study	Sub-themes	Time since dx/tx	Sample specifically long-term
<i>Searching for meaning – cause</i>									
Stewart <i>et al.</i>	2001	Canada	Breast	Quantitative Cross-sectional Survey by mail Researcher-constructed instruments	-	Meaning – causal attribution of cancer and recurrence	-	At least 2 years post-diagnosis (mean 8.6 years post-diagnosis)	x
Dirksen	1995	USA	Malignant melanoma	Quantitative Cross-sectional Survey face-to-face Validated and researcher-constructed instruments	Attribution theory	Meaning – causal attribution of cancer	-	At least 5 years post-diagnosis (mean 9 years post-diagnosis)	Long-term
<i>Searching for meaning – significance</i>									
Kahana <i>et al.</i>	2011	USA	Breast, colorectal and prostate	Quantitative Cross-sectional Survey face-to-face Validated and researcher-constructed instruments	-	Meaning – altered life perspective after cancer	Impact on self	5 years or more post-diagnosis (mean 10.4 years post-diagnosis)	x

Author(s)	Year	Country	Cancer-type(s)	Methods	Specified theoretical framework	Main focus of study	Sub-themes	Time since dx/tx	Sample specifically long-term
Schroevers <i>et al.</i>	2011	Netherlands	Various (majority lymphoma)	Quantitative Cross-sectional Survey by mail Validated and researcher-constructed instruments	-	Meaning – positive and negative changes after cancer	Impact on self	Mean 7.3 years post-diagnosis (range < 2 years to > 5 years post-diagnosis)	x
Jansen <i>et al.</i>	2011	Germany	Colorectal	Quantitative Cross-sectional Survey by mail Validated and researcher-constructed instruments	-	Meaning – benefit-finding and post-traumatic growth	Impact on self, relationships	5 years post-diagnosis (mean 5.4 years post-diagnosis)	Long-term
Bishop <i>et al.</i>	2011	USA	Blood and breast	Qualitative Cross-sectional Semi-structured, individual telephone interviews with survivor-spouse pairs	Post-traumatic growth theory guided interview schedule	Meaning – positive and negative life changes after cancer	Impact on self	At least 5 years post-blood/marrow transplant (mean 13 years post-diagnosis)	Long-term
Helgeson	2010	USA	Breast	Quantitative Cross-sectional Survey face-to-face Validated and researcher-constructed instruments	-	Meaning – positive growth after cancer	Impact on self	At least 10 years post-diagnosis (mean 10.58 years post-diagnosis)	Long-term

Author(s)	Year	Country	Cancer-type(s)	Methods	Specified theoretical framework	Main focus of study	Sub-themes	Time since dx/tx	Sample specifically long-term
Lelorain <i>et al.</i>	2010	France	Breast	Quantitative Cross-sectional Survey by mail Validated and researcher- constructed instruments	-	Meaning – post-traumatic growth	Impact on self	Mean 10 years post-diagnosis (range 5 to 15 years)	Long-term
Alfano <i>et al.</i>	2009	USA	Breast	Quantitative Cross-sectional Survey by mail Validated and researcher- constructed instruments	-	Meaning – positive lifestyle change after cancer	-	Mean 12 years post-diagnosis (Range 9.4 – 16.5 years)	Long-term
Sekse <i>et al.</i>	2009	Norway	Gynaecological	Qualitative Multiple, in-depth interviews	Danish life philosophy	Meaning – cancer as a life-changing process	Impact on self	Between 5 and 6 years post-treatment	Long-term
Mols <i>et al.</i>	2009	Netherlands	Breast	Quantitative Cross-sectional Survey by mail Validated instruments	-	Meaning – benefit-finding and post-traumatic growth	Impact on self, relationships	10 years post-diagnosis	Long-term
Bussing & Fischer	2009	Germany	Various (largest % breast)	Quantitative Cross-sectional Survey by mail Validated instruments	Lipowski's (1970) categories for meaning of illness	Meaning – interpretation/meaning of cancer	-	Mean 10.9 years post-diagnosis (±6.4 years)	x

Author(s)	Year	Country	Cancer-type(s)	Methods	Specified theoretical framework	Main focus of study	Sub-themes	Time since dx/tx	Sample specifically long-term
Zebrack <i>et al.</i>	2008	USA	Various (breast, colorectal, lymphoma & prostate)	Quantitative Cross-sectional Survey by mail Validated instruments	-	Meaning – impact of cancer and post-traumatic growth	-	5 to 10 years post-diagnosis (mean 7.67 years post-diagnosis)	Long-term
Greenwald & McCorkle	2007	USA	Cervical	Quantitative Cross-sectional Survey face-to-face Validated instruments	-	Meaning – life changes after cancer	Relationships	Between 6 and 29 years post-diagnosis	Long-term
Foley <i>et al.</i>	2006	USA	Various (breast, colorectal, gynaecological, head & neck, prostate & bladder)	Mixed methods Cross-sectional Self-administered survey, validated instruments Semi-structured, face-to-face interview	-	Meaning of the cancer experience	Impact on self, relationships	5 years or more post-diagnosis (mean 7.7 years post-diagnosis)	Long-term
Schroevers <i>et al.</i>	2006	Netherlands	Various (largest % breast)	Mixed methods Longitudinal Self-administered survey, validated instruments Semi-structured interview Open-ended interview	Moos and Schaefer's (1993) conceptual model of stress and adaptation	Meaning - life changes after cancer	Impact on self, relationships	8 years post-diagnosis	Long-term

Author(s)	Year	Country	Cancer-type(s)	Methods	Specified theoretical framework	Main focus of study	Sub-themes	Time since dx/tx	Sample specifically long-term
Fleer <i>et al.</i>	2006	Netherlands	Testicular	Quantitative Cross-sectional Survey by mail Validated and researcher- constructed instruments	-	Meaning – changes in outlook on life after cancer	Impact on self	Mean 10 years post-treatment (3 months-24 years)	x
Tomich <i>et al.</i>	2005	USA	Breast	Quantitative Cross-sectional Survey face-to-face Researcher-constructed instruments Comparison with healthy controls	-	Meaning – positive and negative changes after cancer	Impact on self, relationships	Diagnosed at least 5 years previously	Long-term
McGrath	2004a	Australia	Haematological	Qualitative Cross-sectional Open-ended, narrative interviews	-	Meaning – positive outcomes from a spiritual perspective	Impact on self, relationships	Two thirds of the sample were 5 years or more post-tx (8/12)	x
McGrath	2004b	Australia	Haematological	Qualitative Cross-sectional Open-ended, narrative interviews	-	Meaning – cancer as a spiritual journey	Impact on self	Two thirds of the sample were 5 years or more post-tx (8/12)	x

Author(s)	Year	Country	Cancer-type(s)	Methods	Specified theoretical framework	Main focus of study	Sub-themes	Time since dx/tx	Sample specifically long-term
Sinding & Gray	2004	Canada	Breast	Qualitative Multiple sources of data, including journals and a research-based play	-	Meaning – experiences after cancer	Impact on self, relationships	Five years or more post-diagnosis (range 5 – 15 years)	Long-term
Bowman <i>et al.</i>	2003	USA	Various (largest % breast)	Quantitative Cross-sectional Survey face-to-face Researcher-constructed instruments	Lazarus & Folkman's (1984) stress-appraisal-coping framework	Meaning – appraisal of the cancer experience	-	5 years or more post-treatment (Long-term
Tomich & Helgeson	2002	USA	Breast	Quantitative Cross-sectional Survey administered face-to-face Researcher-constructed instruments Comparison with healthy controls	-	Meaning – perceived benefits after cancer, impact on meaning of life	-	Diagnosed 5 and a half years prior to study	Long-term
Dow <i>et al.</i>	1999	USA	Various (largest % breast)	Qualitative Cross-sectional Open-ended questions – written responses	Quality of life (Ferrell et al, 1997)	Meaning – of quality of life after cancer	-	Mean 6.7 years post-diagnosis (range 4 months – 45 years)	x

Author(s)	Year	Country	Cancer-type(s)	Methods	Specified theoretical framework	Main focus of study	Sub-themes	Time since dx/tx	Sample specifically long-term
Utley	1999	USA	Breast	Qualitative Cross-sectional In-depth interviews	-	Meaning – how women perceive cancer, the nature of the cancer experience	-	Diagnosed at least 5 years previously (range 5.5 to 29 years post-diagnosis)	Long-term
Pelusi	1997	USA	Breast	Qualitative Cross-sectional In-depth interviews	-	Meaning – the lived experience of surviving cancer	Impact on self, relationships	Mean 7.6 years post-treatment (range 2-15 years)	x
Carter	1993	USA	Breast	Qualitative Multiple, semi-structured interviews	-	Meaning – the daily lived experience of cancer	Impact on self	Diagnosed at least 5 years previously (range 5 to 26 years)	Long-term
<i>Impact on self</i>									
Khan <i>et al.</i>	2012	UK	Breast, colorectal & prostate	Qualitative Cross-sectional In-depth interviews	-	Impact on self – identification with the survivor identity		Diagnosed at least 5 years previously (range 5 to 22 years post-diagnosis)	Long-term

Author(s)	Year	Country	Cancer-type(s)	Methods	Specified theoretical framework	Main focus of study	Sub-themes	Time since dx/tx	Sample specifically long-term
Morris <i>et al.</i>	2011	Australia	Breast	Qualitative Cross-sectional Semi-structured interviews and written narratives	-	Impact on self – identification with the survivor identity	Relationships, meaning	Mean 6.39 years post-diagnosis	x
Hubbard & Forbat	2011	UK	Various (largest % breast; prostate, colorectal, lung and rarer cancers)	Qualitative Cross-sectional Written narratives	Biographical disruption (Bury, 1982)	Impact on self – experience of living with cancer; how life has changed after cancer	Relationships	Over half the sample were 6 years or more post-diagnosis	x
Helgeson	2011	USA	Breast	Quantitative Cross-sectional Survey face-to-face Validated and researcher-constructed instruments	-	Impact on self – identification with the survivor identity (survivor centrality)	-	10 years post-diagnosis (mean 10.58 years post-diagnosis)	Long-term
Sekse <i>et al.</i>	2010	Norway	Gynaecological	Qualitative Multiple in-depth interviews	-	Impact on self – lived experience of cancer, body image	Meaning	Between 5 and 6 years post-treatment	Long-term
Skaali <i>et al.</i>	2009	Norway	Testicular	Quantitative Cross-sectional Survey by mail Validated instruments Sub-sample had a psychiatric interview	-	Impact on self – fear of recurrence	-	Mean 11.4 years post-diagnosis (define long-term as at least 5 years post-diagnosis)	Long-term

Author(s)	Year	Country	Cancer-type(s)	Methods	Specified theoretical framework	Main focus of study	Sub-themes	Time since dx/tx	Sample specifically long-term
Deimling <i>et al.</i>	2007	USA	Various (largest % breast)	Quantitative Cross-sectional Findings from 2 studies Surveys face-to-face Validated and researcher-constructed instruments	Identity theory (Cooley, Mead)	Impact on self - identification with the survivor identity	-	At least 5 years post-diagnosis (mean not presented)	Long-term
Thomas-Maclean	2005	Canada	Breast	Qualitative Multiple in-depth interviews	-	Impact on self – embodiment, changes to body and appearance	Relationships	Over half the sample were 5 years or more post-diagnosis (range 1 to 24 years)	x
Gil <i>et al.</i>	2004	USA	Breast	Quantitative Longitudinal Survey by telephone, Researcher-constructed instruments	-	Impact on self – triggers of uncertainty about recurrence	-	Mean 6.8 years post-diagnosis (range 5 to 9 years)	Long-term
Rozmovits & Ziebland	2004	UK	Colorectal	Qualitative Cross-sectional Narrative interviews	The physical and social body (Douglas), civilisation and adulthood (Elias)	Impact on self – loss of adulthood due to reorientation of life around bowel habit	Relationships	Short and long-term survivors (distinguish between short and long-term in analysis)	x

Author(s)	Year	Country	Cancer-type(s)	Methods	Specified theoretical framework	Main focus of study	Sub-themes	Time since dx/tx	Sample specifically long-term
Langellier	2001	USA	Breast	Qualitative Case study Narrative interviews	-	Impact on self – body image	-	Case was 10 years post-diagnosis	Long-term
Shapiro <i>et al.</i>	1997	Canada	Breast	Qualitative Cross-sectional Narrative, in-depth interviews with survivors and spouses	-	Impact on self – perceived change in identity	Meaning, relationships	2 women diagnosed 5 years earlier, one 2 years earlier	x
<i>Interpersonal relationships</i>									
Walker & Robinson	2012	Canada	Prostate	Qualitative Cross-sectional Unstructured interviews with couples	-	Impact on the partner relationship – sexual adjustment	Impact on self - masculinity	Mean not presented (range 8 months to 15 years post-diagnosis)	x
Ramirez <i>et al.</i>	2009	USA	Colorectal	Qualitative Cross-sectional In-depth interviews	-	Impact on the partner relationship – sexual functioning	Impact on self – body image, femininity	At least 5 years post-diagnosis	Long-term
Sanders <i>et al.</i>	2006	USA	Prostate	Qualitative Cross-sectional Focus groups with couples	-	Impact on the partner relationship – sexual functioning and intimacy	-	Mean not presented (range 1.5 to 8 years post-treatment)	x

Author(s)	Year	Country	Cancer-type(s)	Methods	Specified theoretical framework	Main focus of study	Sub-themes	Time since dx/tx	Sample specifically long-term
Tuinman <i>et al.</i>	2005	Netherlands	Testicular	Quantitative Cross-sectional Survey by mail to survivors and their partners Validated and researcher-constructed instruments	-	Impact on the partner relationship – marital and sexual satisfaction	-	Mean 9.3 years post-treatment (range 0.5 to 23.8 years)	x

appeared across themes. This being said, the figures presented in Table 3.1 have been calculated according to the main focus of the paper. The main focus of about two thirds of the papers was on searching for meaning in the cancer experience, whilst a quarter explored the impact of cancer on self. Very few papers focused specifically on the impact of cancer on interpersonal relationships during long-term survivorship. The quality of studies was not appraised using specific criteria. As relatively few papers were identified, a decision was made to review all studies that met the inclusion criteria, but highlight their methodological limitations as part of the review.

Theme 1: Searching for meaning in the cancer experience

Background

We are motivated to find meaning in our lives, more so after experiencing trauma or stressful events (Frankl 2004). Park and Folkman (1997: 116) highlight the 'dynamic nature of people's responses to stressful events'. Their stress, appraisal and coping model points to 'the central role of reappraisal and the importance of achieving congruence between an individual's *global* meaning and the *situational* (appraised) meaning of a particular event' (Park and Folkman, 1997: 116). Meaning in their model refers to 'perceptions of significance' of that event (1997: 116).

Global meaning is defined as 'people's basic goals and fundamental assumptions, beliefs, and expectations about the world. Global meaning influences people's understanding of the past and the present, and it influences their expectations regarding the future' (Park and Folkman, 1997: 116). Park and Folkman argue that global meaning develops through life experience. *Situational* meaning refers to: 'the interaction of a person's global beliefs and goals and the circumstances of a particular person-environment

transaction' (Park and Folkman, 1997: 121). Distress, loss of control, and feelings of loss can occur when there is incongruence between global and situational meaning. Searching for meaning therefore aims to integrate situational and global meaning i.e. 'rectify the discrepancy between one's current situation and desired goals' (1997: 124). Searching for meaning is a 'process through which people evaluate the meaning of a specific event with respect to its personal significance' (1997: 122). It is a personal process, which explains why an event might be stressful to one person, but not another. Equally, it explains why an event may be stressful to the same person at one point in their life, but not another.

Tedeschi and Calhoun (1995) argue that positive growth and transformation can occur in those who have faced traumatic events. However, traumatic events such as cancer can also have negative consequences. They postulate that 'it is the very act of struggling with the many negative consequences of traumatic events that makes possible the varied forms of psychological growth' (Tedeschi and Calhoun: 1995: 28) i.e. trying to reconcile global and situational meaning can lead to personal growth. They report three groups of benefits from traumatic experiences: perceived changes in self, a changed sense of relationship with others and a changed philosophy of life.

Here it is important to make the distinction between *post-traumatic growth* and *benefit-finding*. Thornton (2002) acknowledges that it is difficult to synthesise literature on positive changes associated with a cancer diagnosis as there is such definitional and methodological variability. A variety of terms are used across studies including: positive changes, benefit-construal, benefit-finding, post-traumatic growth, thriving, finding meaning and resilience. Thornton suggests benefit-finding and meaning-making are used interchangeably to highlight how survivors 'find something positive in their struggle with cancer' (2002: 154). However, to be more specific, post-traumatic growth is 'benefits associated with changes in life perspective, interpersonal relationships, and self perception' (Jansen *et al.*, 2011: 1158)

(Tedeschi and Calhoun's definition). Benefit-finding, in contrast is 'the process in which the patient re-assigns positive value to the illness based on the benefits he or she identifies' (Jansen *et al.*, 2011: 1158). Benefit-finding is said to start soon after exposure to a traumatic event, such as a cancer diagnosis, whereas post-traumatic growth may develop years after diagnosis (Jansen *et al.* 2011).

Searching for meaning in the cancer experience

Searching for meaning is said to be a significant part of the cancer experience, as cancer threatens the basic assumption that life is meaningful (Taylor 1995, Thornton 2002). Doyle (2008) argues that 'cancer is an extreme experience that disrupts people's lives and sense of identity' (2008: 504), and is therefore a life-changing event. Historically, society has equated cancer with death. As such, research has focused on the negative implications of a cancer diagnosis. However, as more people began to survive the disease, there was a shift to researching the positive benefits of cancer and a prevailing view that patients had to adopt a positive attitude and engage in positive thinking if they wanted to survive (Tod *et al.* 2011). Today we are witnessing a further shift, to a more tempered view, with some researchers exploring the duality of benefits and losses associated with a cancer diagnosis, acknowledging that cancer can lead to both positive and negative changes, often simultaneously (Pelusi 1997, Tomich *et al.* 2005, Bertero and Wilmoth 2007, Doyle 2008, Sekse *et al.* 2009, Helgeson 2010, Kahana *et al.* 2011, Schroevers *et al.* 2011). Kahana *et al.* (2011) highlight the 'spectrum of changes in one's life perspective and identity' (2011: 211) as a result of a cancer diagnosis, and use the term 'post-traumatic transformation' rather than the solely positive 'post-traumatic growth' or negative 'post-traumatic stress' to demonstrate that a range of positive and negative transformations can occur. However, it is important to highlight that, for some survivors, the cancer experience may not be life-altering at all.

Searching for a cause and searching for the significance of a cancer diagnosis

Elizabeth Taylor (1995) conducted a literature review on searching for meaning across the cancer trajectory. She referred to Shelley Taylor's seminal work on cognitive adaptation, which differentiates between searching for a *cause* and searching for the *significance* of an experience (Taylor 1983). In doing so, Taylor (1995) identified four ways cancer survivors conceptualise 'search for meaning': causal explanations, selective incidence, responsibility and significance.

Searching for the cause of cancer

Causal explanations focus on asking why events like cancer happen (Taylor 1995). According to Taylor, these explanations can change over time, and are often influenced by social and cultural background. *Selective incidence* involves asking 'why me?' Taylor asserts that this is 'perhaps the most distressing aspect affecting meaning-making' (1995: 34) as medicine often cannot explain *why* someone was diagnosed. Taylor suggests that asking 'why not me?' may relieve distress as it 'reflects a recognition of not being alone... not the only ones singled out' (1995: 34). *Responsibility* focuses on questions of personal responsibility for the event, such as chance, God, or the environment. Taylor (1995) highlights two types of self-blame: behavioural and characterological (personal characteristics). Behavioural self-blame is said to be more adaptive as it provides a sense of being able to do something to prevent the event from happening again (Taylor 1995).

Several commentators have discussed the inadequacy of medical accounts to explain the causes and consequences of chronic illness (Bury 1982, Williams 1984, Kleinman 1988, Lawton 2003, Lewis 2007). Individuals turn to their own lay knowledge to find meaning in events. For example, events from the past

may be used to try and explain disease, such as the existence of hereditary conditions in families. From the perspective of those affected by cancer, it is often not possible to find a medical explanation for the onset of the disease, which can lead to a sense of vulnerability and uncertainty (Fleer *et al.* 2006). Individuals and their families may develop their own reasons in order to try to give meaning to their illness (Die-Trill 2000). Perceived causes of cancer include: chance, stress, having too many children, a bad personality, physical factors, heredity, religion, environmental pollution, homosexuality and lifestyle (Die-Trill 2000). Some cancer patients may blame themselves or others for their cancer, interpreting cancer as a form of punishment (Die-Trill 2000). This being said, research on causal attributions in cancer is scarce. Indeed, I only identified two studies that explicitly explored causal attribution in long-term cancer survivorship (Dirksen 1995, Stewart *et al.* 2001).

Searching for a cause during long-term survivorship

Dirksen (1995) conducted a quantitative study to explore the search for meaning in long-term survivors of malignant melanoma. Her study was based on the different ways Taylor (1995) conceptualised the search for meaning and was underpinned by attribution theory¹⁹. Dirksen argues that developing a theory or reason why cancer developed may provide a sense of security and reduce worry about recurrence. She found that just over half of survivors searched for meaning, which resulted in an identifiable cause of cancer. Those who took responsibility for their cancer expressed a greater search for meaning than those who did not blame themselves. However, most did not self-blame. Indeed, beliefs about cause were mainly seen to be out of survivors' control. Sixty-eight percent of the sample did not accept personal responsibility for their cancer, which Dirksen found surprising as malignant melanoma has known causes, such as staying out in the sun.

¹⁹ Attribution theory: the search for the cause of an event that is unexpected/stressful in an attempt to understand and gain control.

In a study by Stewart *et al.* (2001), eighty-five percent of women attributed some cause to their breast cancer. They found that many women believed stress caused their cancer (42%). Other cited causes were genetics, environment, hormones, diet and breast trauma (Stewart *et al.* 2001). When asked about their perceived personal risk of recurrence, about 80% felt it was average or below average. Perceived chance of recurrence was not associated with attribution of cause or prevention (Stewart *et al.* 2001). Eighty-seven percent of women had a personal belief about what prevented recurrence. Positive attitude was the most common response, followed by diet, a healthy lifestyle, exercise, stress reduction, prayer, complementary therapies, luck and Tamoxifen (Stewart *et al.* 2001). Women diagnosed over five years previously were more likely to believe that a healthy lifestyle and prayer prevented recurrence. The researchers found that 95% followed a healthy diet, the majority also took vitamins and exercised regularly. It therefore appears that managing the perceived causes of cancer and ways to prevent recurrence focus on taking personal control over one's lifestyle.

Searching for the significance of cancer during long-term survivorship

Research suggests that many people diagnosed with cancer eventually find it to be a positively transformative experience. Indeed, surviving cancer can be a turning point – an opportunity for survivors to reflect on life and take a new path (Vachon 2001). However, as already discussed, cancer can also have negative implications. This section draws attention to the positive and negative impact of searching for, and finding, meaning during the long-term survivorship phase.

Several studies have shown that a diagnosis of cancer can lead to a changed outlook on life or life perspective (Pelusi 1997, McGrath 2004a, Sinding and Gray 2004, Fleer *et al.* 2006, Mols *et al.* 2009b, Helgeson 2010, Bishop *et al.* 2011, Kahana *et al.* 2011, Schroevers *et al.* 2011). This may include a greater appreciation for life, for each day, and nature, not taking life for granted and

realising that every day is precious (Carter 1993, Utley 1999, Tomich *et al.* 2005, Fleer *et al.* 2006, Schroevers *et al.* 2006, Greenwald and McCorkle 2007, Mols *et al.* 2009b, Sekse *et al.* 2009, Helgeson 2010, Lelorain *et al.* 2010, Bishop *et al.* 2011, Jansen *et al.* 2011). Jansen *et al.* (2011) found that survivors have a new-found purpose in life, whilst McGrath (2004a) reported that survivors live life to the full and Mols *et al.* (2009b) described how survivors feel a greater satisfaction with life. Several studies have also reported how cancer can lead to changes to religious views (Tomich *et al.* 2005, Greenwald and McCorkle 2007, Kahana *et al.* 2011).

Survivors speak of reprioritising goals, for example, life goals over career, and changed values and priorities, focusing on the important things in life, and showing less concern for trivial matters (Carter 1993, Shapiro *et al.* 1997, Dow *et al.* 1999, Tomich *et al.* 2005, Bishop *et al.* 2011, Kahana *et al.* 2011). Some studies have touched on how survivors now accept life situations that present themselves, for example, taking things as they come and feeling they can handle difficult situations (Greenwald and McCorkle 2007, Jansen *et al.* 2011). Changes to survivors' lifestyles are another area of reported growth during long-term survivorship. Studies have reported health behaviour change, particularly dietary changes and leading a more active lifestyle (Carter 1993, Shapiro *et al.* 1997, Dow *et al.* 1999, McGrath 2004b, Tomich *et al.* 2005, Greenwald and McCorkle 2007, Alfano *et al.* 2009, Mols *et al.* 2009b, Bishop *et al.* 2011).

Despite the focus on searching for meaning as a positive experience, some theorists suggest it can be a negative process if meaning is not found (Park and Folkman 1997). Park and Folkman (1997) assert that those unable to make sense of an experience may be caught in a cycle of continuously trying to find meaning, which is maladaptive. This perspective has rarely been explored with specific reference to long-term cancer survivors. However, in one study, Tomich and Helgeson (2002) found that long-term breast cancer survivors who were still searching for meaning five years after diagnosis had

poorer mental functioning, less positive affect and more negative affect, than healthy controls. They also concluded that a continued, unresolved search for meaning was related to poor adjustment (Tomich and Helgeson 2002).

Theme 2: Impact of cancer on self

Background

Bury's (1982) seminal work on chronic illness as 'biographical disruption' has been used as a descriptive and analytical tool in cancer research, despite the debate regarding whether cancer can be classified as a chronic illness (Tritter and Calnan 2002, Hubbard *et al.* 2010). Individuals experience disruption to 'taken for granted assumptions' - the way they thought everyday life would continue is disrupted by illness. This forces ill people to renegotiate their self-concept and mobilise 'cognitive and material resources' in response to the disruption (Bury, 1982). This may include searching for an explanation for, or meaning of, the illness, as well as rearranging priorities and obligations. Therefore Bury asserts that the onset of, and day-to-day living with, chronic illness is not just an assault on the physical self but also an assault on identity (Bury, 1991). Charmaz (1983) also explored the impact chronic illness and, in particular, suffering, can have on one's self-concept. People suffering from chronic illness may experience 'loss of self' (diminished self-concept) and 'a crumbling away of their former self-images without simultaneous development of equally valued new ones' (1983: 168).

Many cancer survivors feel they have changed as a result of the illness experience – in terms of their own sense of self and in relation to others (McGrath 2004b, McGrath 2004a). Bertero and Wilmoth (2007) refer to the 'redefinition of self' after cancer. The negative impact on self is evident in the literature, with some survivors feeling 'branded' or 'marked' by cancer, which

affects their sense of personal and social identity and, subsequently, their interactions with others (Mathieson and Stam 1995, Little *et al.* 1998, Langellier 2001, McKenzie and Crouch 2004, Kaiser 2008). However, as already highlighted, cancer can lead to positive transformation, and this includes to one's self-concept. Thornton's (2002) literature review highlights benefits to self including: increased inner strength, independence, caring for one's own needs, taking more time for self, increased self-worth, and self-respect. The following section briefly summarises the positive and negative impact of cancer on self experienced during long-term cancer survivorship.

Impact of cancer on self during long-term cancer survivorship

Personal identity

The positive impact on self has been reported in several studies on long-term cancer survivors and focuses on the redefinition of self and personal transformation. This may include spiritual development (McGrath 2004b, Jansen *et al.* 2011). Indeed, Vachon (2001) described how cancer can be a 'spiritually transformative event', with survivors feeling a sense of higher purpose and connection to a higher power/being.

Research has shown that cancer survivors have a clearer sense of self and increased confidence to manage life crises (Carter 1993). Survivors have reported increased inner strength: they feel stronger, are more outspoken, decisive, confident, assertive, independent and less dependent on the approval of others (McGrath 2004b, Schroevers *et al.* 2006, Mols *et al.* 2009b, Lelorain *et al.* 2010, Schroevers *et al.* 2011, Hubbard and Forbat 2012). Other examples of self-improvement include survivors caring for their own needs, doing what they want to and taking more time for themselves. They may also be more emotionally and sensitively aware. This can lead to survivors feeling

happier and more content (Tomich *et al.* 2005, Mols *et al.* 2009b, Sekse *et al.* 2009, Helgeson 2010, Helgeson 2011, Hubbard and Forbat 2012).

The negative impact on self includes living with uncertainty, as a result of an awareness of one's own mortality and fear of recurrence; a loss of physical health; an altered body image; loss of sexuality and masculinity/femininity; and negative emotional changes such as feeling more pessimistic. Survivors have to face the unknown and live with a sense of vulnerability during the long-term survivorship phase. These are all threats to identity which can lead to a struggle to maintain that identity which, in turn, can cause suffering, loss of values and loss of relationships (Hench and Danielson 2009).

As mentioned previously, the Sword of Damocles is widely referred to in the cancer literature, inferring that the threat of recurrence hangs precariously over the lives of survivors (Koocher and O'Malley 1981, Frank 1995, Zebrack 2000b, Stephens 2004, Kaiser 2008). In addition, cancer survivors have been made 'mortality salient'— they have confronted death and recognise that they will do so again at some point in the future, although they do not know when (Little and Sayers 2004b, Little and Sayers 2004a). Several studies have reported that fear of recurrence, illness uncertainty and vulnerability can persist into long-term survivorship (Pelusi 1997, Gil *et al.* 2004, McGrath 2004b, Fleer *et al.* 2006, Schroevers *et al.* 2006, Bertero and Wilmoth 2007, Doyle 2008, Sekse *et al.* 2009, Skaali *et al.* 2009, Helgeson 2010, Bishop *et al.* 2011, Kahana *et al.* 2011, Hubbard and Forbat 2012).

Several studies have explored the impact of altered body image on survivors' sense of self (Langellier 2001, Rozmovits and Ziebland 2004, Sekse *et al.* 2009, Walker and Robinson 2012). Rozmovits and Ziebland described the consequences of treatment and subsequent bodily function on the adult identity of colorectal cancer survivors. Survivors described a 'reorientation of life around bowel habit' with a corresponding loss of dignity, privacy, independence and sexual confidence. However, they pointed out that many

people make a good recovery and re-establish normal eating and bowel habits and can therefore 'reassume an adult identity' (2004: 202) without a loss of professional identity, loss of ability to socialise or disruption to sexual identity (Rozmovits and Ziebland 2004).

Sekse *et al.* (2010) explored women's experiences five years post-treatment for gynaecological cancer and one of the themes identified was 'living in a changed female body.' They found that women's feelings of femininity, discussed in terms of physical looks, were little affected by treatment. Women who had a hysterectomy compared themselves to how a woman might feel after a mastectomy for breast cancer. They perceived that losing a breast would have a greater impact on femininity (Sekse *et al.* 2010). Indeed, Langellier (2001) presented a case study exploring the impact of breast cancer on 'Rhea' – a woman in her early forties who was ten years post-diagnosis. Langellier discussed how Rhea's body had been marked by breast cancer and its treatment (radiation and mastectomy). Rhea's narrative highlighted her 'struggle to take her body back from the spoils of disease, surgery, and the multiple stigmatising forces of discourse' (2001: 170). To do so, Rhea decided not to have a reconstruction but instead had a tattoo on her mastectomy scar, over which she wears a prosthesis. Rhea responded to the markings of breast cancer and mastectomy with her own 'body marking' (Langellier 2001). She 'effectively "owns" her disease and scar, personalising her illness' (2001: 174).

A study by Walker and Robinson (2012) explored sexual adjustment amongst men treated with hormone therapy for prostate cancer. They highlighted that the side effects of androgen deprivation therapy (ADT), which include erectile dysfunction, loss of libido, hot flashes and bodily feminisation, can affect a man's sense of masculinity. This resulted in a loss of self-esteem and impacted on sexual function.

It should be noted that not everyone affected by cancer experiences changes to their sense of self. Shapiro *et al.* (1997) undertook in-depth interviews to

explore the experiences of three long-term breast cancer survivors and their partners. They were particularly interested in changes to identity. Three narrative themes were found in the data: *back to 'normal', rebirth and turning point* (Shapiro *et al.* 1997). Accounts showed variation in perceived changes to identity – two survivors felt changed by the experience, whilst the other did not. Regarding the theme '*back to normal*', one woman felt back to her 'old self' when treatment and recovery were completed (Shapiro *et al.* 1997). Her support network, maintaining contact with work and continuing social activities supported the maintenance of her 'old self'. This woman felt she was fundamentally the same person, that the experience had not changed her and that she therefore did not want to be identified by the experience. She experienced a temporary disruption – albeit a 'horrible' one – but her core sense of self was unchanged.

Illness identity

The concept of the 'sick role' was conceived by Talcott Parsons in 1951. He argued that illness has a social, as well as individual, dimension. Individuals learn what society expects of them when they are sick. If they fail to conform, they may be stigmatised for 'deviant behaviour' (Giddens 2009). However, Radley suggested individuals often refuse to occupy the 'sick role' for fear of such stigmatisation (Radley 1994). Yet, he also argued that despite whether or not a person is symptomatic, they are still subject to 'social categorisation' (Radley, 1994: 4). Indeed, Little *et al.* (1998) refer to the 'adhesiveness' of the cancer label, which persists long after treatment has finished (1998: 1486). McKenzie and Crouch (2004) also suggest survivors are 'permanently branded by the disease' (2004: 140) whilst Mathieson and Stam (1995) argue some survivors feel 'contaminated' by cancer. Some individuals resist the 'cancer survivor' label (Sinding and Gray 2004, Kaiser 2008, Leigh 2008). Indeed, Leigh highlighted that many survivors 'loathe' the term (2008: 248). Kaiser found that, despite the positive connotations implied by the term 'cancer survivor', some women with breast cancer actively reject the label as they do not want

to be defined by their illness. A small number of studies have explored the adoption and/or rejection of the 'cancer survivor' identity during long-term cancer survivorship, and they are briefly discussed here (Deimling *et al.* 2007, Helgeson 2011, Morris *et al.* 2011, Khan *et al.* 2012).

Deimling *et al.* (2007) reported that older adults who had survived for at least five years after a cancer diagnosis identified themselves as 'cancer survivors' and/or 'ex-patients' rather than 'victims' or 'patients'. Being a survivor was an important part of who they were, but they were not overly concerned about how others view them. More recently, Helgeson (2011) conducted a quantitative study exploring the extent to which long-term breast cancer survivors (ten years post-diagnosis) integrated cancer into their self-concept (survivor centrality), and what factors predicted survivor centrality. Helgeson found that women varied in the extent to which they defined themselves in terms of their breast cancer. Younger women had higher survivor centrality scores, but no other demographic or cancer-related variables were associated with this construct. Helgeson concluded that she 'did not learn a lot about who is more likely to define themselves in terms of cancer survivorship' (2011: 522).

Morris *et al.* (2011) qualitatively explored adoption of survivor identity after participating in a challenge-based peer-support programme. Overcoming challenges through the event, and the opportunity to form a connection with other survivors, solidified the survivor identity for those women who considered themselves survivors prior to the peer-support challenge. Some women attached new meaning to their cancer experience, and developed a new-found positive identification with the term 'survivor' after the challenge (Morris *et al.* 2011). Meeting other survivors 'was central to women reappraising their own situation positively through the social comparison process of upward identification' (2011: 668). Those that identified with the term 'survivor' attributed positive meaning to the term, highlighting feelings of strength and group membership, which in turn were strategies to actively

cope with the challenges of their cancer experience. However, there were some women who did not identify with the term, either because they were worried that they would be seen as a victim of cancer, or because they felt they had been treated for an illness and it had gone, therefore they were no longer trying to survive anything (Morris *et al.* 2011).

The only UK-based study to explore the 'cancer survivor' identity was conducted by Khan *et al.* (2012). Their qualitative study of forty people at least five years post-diagnosis for breast, colorectal or prostate cancer found that most respondents did not endorse the term 'cancer survivor'. Various reasons were highlighted. Participants felt that the term 'survivor' implied cure, they did not want to be defined by the cancer experience, they felt others were more deserving of the label (such as those with other chronic illnesses), they had experienced more challenging events in their lives than cancer or that the label implied an advocacy role that they did not aspire to (Khan *et al.* 2012). Khan *et al.* suggested that more 'descriptive terms' be employed when referring to this population (2012: 184).

Theme 3: Impact of cancer on interpersonal relationships

Background

Illness 'profoundly' influences relationships (Kleinman 1988), with both positive and negative implications. Kleinman argues that 'illness is not simply a personal experience; it is transactional, communicative, profoundly social. The study of illness meanings is not only about one particular individual's experience; it is also very much about social networks, social situations, and different forms of social reality. Illness meanings are shared and negotiated' (1988: 185-186). Illness brings individuals and those close to them 'face to face with the character of their relationships' where disruption of 'normal

rules of reciprocity and mutual support' occurs (Bury, 1982: 169). Therefore, there is a need to understand the 'interlinked lives' of survivors and their loved ones after an experience of cancer (Little and Sayers 2004b).

Impact of cancer on interpersonal relationships

Several literature reviews have been published on the impact of cancer on spousal/partner relationships (and sexual functioning), and social and familial relationships (O'Mahoney and Carroll 1997, Weihs and Reiss 2000, Thaler-DeMers 2001, Thornton 2002, Thornton and Perez 2007, Fossa and Dahl 2008, Hara and Blum 2009, Naaman *et al.* 2009, Wittmann *et al.* 2009). Thornton and Perez (2007) highlight that relatively little research has explored the impact of cancer on relationships beyond diagnosis and treatment. Of the studies that have been conducted on long-term cancer survivors, few focus on the non-sexual aspects of relationships or relationships other than the partner relationship (Thornton and Perez 2007).

Research suggests that there is a socially acceptable way for cancer survivors to act post-treatment (Little *et al.* 1998, Crouch and McKenzie 2000, Little *et al.* 2002, Little 2004, Little and Sayers 2004b, Little and Sayers 2004a, McKenzie 2004, McKenzie and Crouch 2004, Kaiser 2008). Kaiser discusses the 'language of survivorship, how cancer survivors are expected to 'fight the good fight', battle the disease, wage a war on cancer whilst maintaining a positive outlook (2008: 81). Not only is this thought to benefit the cancer survivor in terms of positive adjustment and quality of life post-treatment (Park *et al.* 2009), but it also helps family, friends, etc. feel less anxious and concerned about not just the cancer survivor's future, but also their own. Miles Little and colleagues have explored how cancer survivors' significant others are made 'uncomfortably aware of mortality' – they are made 'mortality salient' (Little and Sayers, 2004b: 1331). Adopting a positive outlook and taking steps to return to 'normality' once treatment is completed, are

said to be 'socially approved' by those close to survivors as they are reassuring and 'keep mortality salience at bay' (Little and Sayers, 2004b: 1336).

So, in this sense, the term 'survivor' is as much for family and friends as it is for the individual diagnosed with the disease. Problems arise, however, if those diagnosed find it difficult to maintain such a positive outlook or seek to find meaning from the experience (Little *et al.* 2002, Little and Sayers 2004b, McKenzie and Crouch 2004, Kaiser 2008). This can lead to unwelcome feelings on the part of 'secondary' survivors, which can lead them to alienate the cancer survivor from 'normal' societal interactions. For example, McKenzie and Crouch studied the impact 'being permanently branded by the disease' can have on relationships (2004: 140). On treatment completion, significant others deem the 'struggle' to be over and expect life to return to normal. However, fear of recurrence, uncertainty and the fact that the survivor has faced their own mortality may result in different emotions on the part of the survivor. A 'mismatch' of emotions and future plans can lead to 'social distancing' in close relationships (McKenzie and Crouch, 2004: 143). Survivors may attempt to control, or mask, their emotions to appear socially acceptable to the 'normal' majority. However, this inability to then communicate their true feelings to those close to them can lead to tension and a breakdown in relationships (Little *et al.* 1998, McKenzie and Crouch 2004).

Despite this, changes in relationships associated with the cancer experience appear to be largely positive (Thornton 2002, Thornton and Perez 2007). As already discussed, Thornton and Perez highlight that positive changes in relationships are one of the most frequently cited domains of benefit-finding.

Impact of cancer on interpersonal relationships during long-term survivorship

Studies have shown that long-term cancer survivors have a greater appreciation for others, show increased compassion, sympathy, concern,

sensitivity and respect, and are less judgemental (McGrath 2004a, Schroevers *et al.* 2006, Jansen *et al.* 2011). More time and effort is invested in relationships which leads to improved relationships with family and friends, and a deeper love for one's spouse and closeness to one's family (McGrath 2004a, Tomich *et al.* 2005, Greenwald and McCorkle 2007, Mols *et al.* 2009b). Cancer survivors are more appreciative of the time they spend with those close to them (Foley *et al.* 2006).

In terms of the negative implications of cancer, body image concerns clearly impact social interaction. For example, as discussed earlier in this chapter, impaired bodily function has been shown to compromise colorectal cancer survivors' ability to work, travel and socialise, albeit temporarily for some (Rozmovits and Ziebland 2004). Thomas-Maclean (2005) reported that women with breast cancer feel they have to appear normal to others, so they engage in 'normalisation' activities, such as wearing a prosthesis, even if it is uncomfortable. The awareness of one's mortality and potential shortened life expectancy can also lead survivors to hold back from making commitments and attachments (Hubbard and Forbat 2012). This can lead to survivors feeling isolated from their social world. Sekse *et al.* (2009) argue that cancer makes women 'more emotionally and sensitively aware' which creates 'a new vulnerability in encounters with others' (2009: 293). Women in their study felt that people would not be able to understand what they had been through, which generated a sense of 'existential loneliness'. Some women talked about how they took on a 'protective role', not sharing their thoughts and feelings with those close to them to protect them from difficult conversations, not just about cancer more generally, but the intimacy and sensitivities surrounding gynaecological cancer (Sekse *et al.* 2009).

Impact of cancer on the spousal/partner relationship during long-term cancer survivorship

Relationships change on all levels of intimacy after a cancer diagnosis (Colyer 1996). Several studies on long-term survivors clearly highlight this sentiment. Sanders *et al.* (2006) reported findings from a study exploring couples' long-term intimacy needs and concerns following prostate cancer. They suggested that 'men and women think and respond very differently to the experience of surviving prostate cancer' (2006: 505). Women felt their roles and responsibilities had changed, from being protected and cared for, to more 'emotional caretaking' (2006: 505). Men reported 'frequent miscommunication' with their partners (2006: 505) and that sex was less romantic and more difficult as a result of the side effects of treatment. Their wives agreed, suggesting that sex had become too 'clinical', and lacked spontaneity (2006: 505). However, men also highlighted the importance and necessity of their wives' support (Sanders *et al.* 2006).

Ramirez *et al.* (2009) published a study exploring the impact of ostomies on sex and body image in female long-term colorectal cancer survivors. They found four categories of sexual experience. First were those who experienced no long-term sexual difficulties, but had a variety of techniques to ensure this was the case, for example, keeping the bag covered/hidden and also having a supportive partner who accepted their changed body and made them feel desirable. Second were those who had long-term difficulties, for example, pain or inability to have sex. For some, this caused disruption and a sense of loss for the intimacy experienced previously, but for others it was not particularly problematic, perhaps because sex had not be an important part of the relationship previously, or they found other ways to show love and intimacy which maintained the relationship. For others, they were grateful to be alive so long-term difficulties were deemed a small price to pay. Third were those for whom age-related, life course changes in sexuality meant sex had changed as a result of getting older rather than surgery. Finally there were

survivors who had no sexual experience post-surgery, i.e. they did not have partners. An ostomy made it difficult to start a new relationship, perhaps because women felt undesirable or had concerns about how to deal with a new partner's reaction. For these women, whilst celibacy was not ideal, it was less complicated than trying to negotiate their altered body image with a new partner. The findings point to the diversity of meaning in sexual relationships for long-term survivors (Ramirez *et al.* 2009).

Walker and Robinson (2012) explored sexual adjustment amongst men treated with hormone therapy for prostate cancer. As already highlighted, the side effects of androgen deprivation therapy (ADT) can affect a man's sense of masculinity and sexuality. This can subsequently impact sexual relationships. All couples said that their relationship had changed since undergoing ADT. They experienced changes to sex, including having to use sex aids and focusing on intimacy, but also grieving the loss of the sexual relationship they had prior to cancer (Walker and Robinson 2012). Couples reported being 'plagued' by unhelpful feelings, including doubt that they were still physically attractive to their partner, grief over the loss of a significant part of their relationship, self-esteem issues and negative expectations about the 'success' of sexual relations. Loss of self-esteem was a key issue for both men and women. Men's loss of self-esteem stemmed from feeling less masculine. Women's loss of self-esteem resulted from their concern that their partner's loss of libido was due to them not finding their partner attractive. One key strategy identified was open communication, which helped 'counter misinterpretations that changes in affection meant a loss of love' (2012: 463).

Impact of cancer on relationships with family and friends during long-term survivorship

Very little research was identified that has explored the impact of cancer on familial relationships during the long-term survivorship phase. In terms of the positive impact on familial relationships, McGrath (2004a) reported that

survivors have a stronger sense of family togetherness, are more aware of reliable friends and family, and have increased respect for others. From a more negative perspective, Pelusi (1997) highlighted that cancer survivors have to mediate the expectations of others. She identified 'a sense of incongruence between [a survivor's] own expectations of what one should experience during survivorship and their perception of what others thought... mediation of such expectations is necessary for relationships to stay viable and significant' (1997: 1348). The women with breast cancer in her study felt that family and friends viewed them differently, for example, not as strong, dependable or capable and that others wanted the old person/life back.

As there is so little research on the impact of cancer on the family, the discussion here focuses on findings from a literature review by Weihs and Reiss (2000), to highlight some of the familial issues experienced across the cancer trajectory. They suggest that cancer creates the potential for loss and separation in families, which can change the life course of that family. To understand the threat of cancer to a family, it is necessary to understand the personal and social context within which cancer arises. As Kleinman (1988) states, illness meanings are shared and negotiated, and one of the sites where such meaning is negotiated is within the family. Weihs and Reiss suggest that 'cancer-related losses of relationships, or painful, maladaptive interchanges during the illness of loved ones in the past may increase the sense of danger from cancer to the family' (2000: 25). They give the example of a patient who feels they will be a burden to their family. That patient may avoid disclosing how distressed they are, which will 'foreclose opportunities for comforting responses' from family members and signal to those family members to separate themselves from the patient. This is an avoidant pattern of relating and leads to a reduction in communication about cancer and therefore reduced opportunity for joint problem-solving (2000: 25). In contrast, increased security within a family may occur if they engage in sensitive patterns of relating ('supportive responding') (2000: 25). Weihs and Reiss state that a family that relates with mutuality, a 'flexible, adaptive pattern of

relational continuity that incorporates change' (2000: 30) is adaptive as it maintains the composition of the family, but changes the 'form or content' of roles and relationships in response to cancer. In other words, cancer requires families to revise the ways they relate to one another. New roles and responsibilities must be 'mutually determined' (2000: 30) to maintain security, attachment and caregiving within the family.

Relationships with other people affected by cancer

A small number of studies have touched on the 'connection' that survivors might develop with other people affected by cancer. As already discussed, long-term survivors may experience isolation and loneliness as they are unable communicate the nature of their cancer experience to those close to them (Pelusi 1997, Sinding and Gray 2004, Sekse *et al.* 2009, Hubbard and Forbat 2012). This is, in part, because those close to the survivor have not been through the experience themselves. The inability to share experiences with those close to them means 'most patients recognised...[they] could only relate directly and with belief to those who had undergone similar experiences' (Little *et al.*, 1998: 1489) i.e. other people affected by cancer. For example, the survivor in Shapiro *et al.*'s (1997) study who experienced breast cancer as a 'turning point' referred to 'a self in process' (1997: 545). This woman remained active and independent during treatment. Her extended support network was not always available and she felt that she needed greater emotional support. She sought peer support and, as a result, developed new relationships. In some instances, survivors find they 'connect' with a range of people that they would not have met had it not been for the cancer experience (McGrath 2004a).

Morris *et al.* (2011) reported that comparing themselves to other survivors helped women with breast cancer reevaluate their own situation more positively – seeing other survivors doing well gave women strength and confidence. In addition, 'group membership' helped women cope with the

challenges of their cancer experience (Morris *et al.* 2011). [See also the discussion of 'communitas' in Chapter 4]. Finally, survivors' may also experience a desire to make a difference to the lives of other people affected by cancer, for example, through cancer volunteer work (McGrath 2004a).

Summary

For some individuals, a diagnosis of cancer has little impact, and 'normal' life resumes post-treatment. For others, cancer redefines who they are, profoundly affecting their outlook on life, identity and relationships - positively and negatively. Therefore, whilst many individuals adjust well to living beyond cancer, there are those who experience substantial 'fallout' (Miller *et al.* 2008). Thornton and Perez (1997) argue that given the majority of survivors describe high levels of relationship quality, questions that should be asked are not how relationships change after cancer, but for whom and why. Equally, Bellizzi (2004), who explored post-traumatic growth in survivors two to nine years post-diagnosis, concluded that research is necessary to understand the process of how, when and why some people thrive after a traumatic event (Bellizzi 2004). To facilitate that understanding, the following section explores the impact of socio-demographic and cancer-related variables and life context on the experience of long-term cancer survivorship.

Understanding the experience of long-term cancer survivorship

Die-Trill (2000) suggests that various socio-demographic and cancer-related factors influence beliefs about cancer causation, including age, gender, personal and familial experience of cancer, socio-economic status, education, cultural and religious background, health and illness-related beliefs, time since diagnosis, site of disease, and knowledge of cancer (Die-Trill 2000). However, what will become evident is the contradictory nature of findings. As a result,

conclusions regarding the impact of these variables on survivors' experiences of long-term survivorship cannot be drawn.

Socio-demographic factors

Gender

Studies suggest gender could influence the meaning ascribed to the long-term cancer survivorship experience. Research has found that women are more likely to derive positive benefits (personal growth and appreciation for life) whereas men are more likely to adopt a 'that's life' approach, meaning that they acknowledge they have gone through a significant event, but it will have neither a positive nor negative effect in the long-term (Foley *et al.*, 2006). Supporting this assertion, being female was positively associated with reporting decision-making transformations in Kahana *et al.*'s (2011) study of long-term breast, colorectal and prostate cancer survivors. However, Dirksen (1995) found gender had no significant correlation with searching for meaning in the experience of malignant melanoma. It has also been argued that research into the meaning of cancer to male survivors is scarce, as the focus has typically been on female, breast cancer survivors (Fleer *et al.* 2006).

Age

Several studies have explored the impact of age on the experience of long-term cancer survivorship (Dirksen 1995, Bowman *et al.* 2003, Fleer *et al.* 2006, Foley *et al.* 2006, Greenwald and McCorkle 2007, Bussing and Fischer 2009, Helgeson 2011, Jansen *et al.* 2011, Kahana *et al.* 2011, Hubbard and Forbat 2012). Bowman *et al.* (2003) reported that older people adjust better to cancer. Using Lazarus and Folkman's (1984) stress-appraisal coping framework to explore stress appraisal of the cancer experience, they found the strongest correlates of stress appraisal were person factors. Older survivors of breast,

prostate and colorectal cancer perceived the disease as less stressful than younger survivors. This is not to say that older people did not experience distress as a result of their diagnosis, but they speculated that for older people, their life stage meant cancer was 'just part of living' (Bowman *et al.*, 2003: 230): 'the cancer experience from years past may be "suppressed" in the face of current, perhaps more debilitating, health conditions and other problems and threats' (2003: 234). For younger people, 'off time' events (those which are not expected) are often more traumatic.

These conclusions support earlier work by Dirksen (1995) who found that younger survivors of malignant melanoma reported a greater search for meaning than older survivors. Later work also corroborates Bowman *et al.*'s (2003) findings. Foley *et al.* (2006) found that older people were more likely to adopt a 'that's life' approach than younger survivors. Foley *et al.* (2006) explained this through the 'frame of reference for life experience' that older people possess. Older survivors compare cancer to other comorbidities and concerns in their life, and what has happened to them over the course of their lives – a frame of reference that younger people do not necessarily have.

However, Foley *et al.* (2006) also found that younger people were more likely to experience positive growth. Kahana *et al.* (2011) concurred, reporting that, even though their study sample comprised older survivors (60+) of breast, prostate and colorectal cancer, the younger respondents reported more post-traumatic transformation. Older survivors of colorectal cancer were also found to report less post-traumatic growth in Jansen *et al.*'s (2011) study and fewer life changes were identified in older women with cervical cancer (Greenwald and McCorkle 2007). Helgeson's (2011) study exploring the extent to which long-term breast cancer survivors integrated cancer into their self-concept (survivor centrality) found that younger women had higher survivor centrality scores i.e. they were more likely to identify as a survivor, but no other demographic variables were associated with this construct.

Hubbard and Forbat (2012) suggested that fear of recurrence may be related to age, with younger survivors reporting fear of recurrence more than older survivors. Indeed, older women with breast cancer reported significantly fewer triggers that remind them of cancer in Gil *et al.*'s (2004) study. However, not all studies have found an association between age and the experience of cancer. For example, Skaali *et al.* (2009) found that age at diagnosis and age at follow-up were not associated with fear of recurrence in long-term testicular cancer survivors, whilst Fleer *et al.* (2006) found that age was not related to meaning of life in testicular cancer survivors.

Relationship status and parenthood

Contradictory findings have been reported with regard to the influence of relationship status and parenthood on the experience of long-term survivorship. For example, whilst married testicular cancer survivors, and those with children, were found to gain more meaning from the cancer experience in a study by Fleer *et al.* (2006), other studies have found no significant association between the search for meaning and partner/marital status (Dirksen 1995) or the interpretation of illness and family status (Bussing and Fischer 2009). Sekse *et al.* (2010) explored women's experiences five years post-treatment for gynaecological cancer and, as mentioned earlier, one of the themes identified was 'living in a changed female body.' They found that the removal of sexual organs did not seem to be an important concern for women who were past childbearing age: 'many regarded their sexual organs as useful for reproduction, suggesting that the feeling of loss seemed minimal... women were focused on getting well' (2010: 5).

Thornton and Perez's (2007) literature review found that survivors in new relationships, or those in relationships troubled prior to diagnosis, may experience higher rates of relationship dysfunction. Their conclusions are supported by research that suggests long-term testicular survivors who start a relationship after completion of treatment are a vulnerable group, as levels of

marital and sexual satisfaction are lower than those for testicular cancer survivors in long-term relationships (Tuinman *et al.* 2005).

Socioeconomic status

The socioeconomic status (SES) of cancer survivors has rarely been studied with respect to the experience of survivorship. To date, research on different facets of SES has been inconclusive. Educational attainment was not related to finding meaning in life or the interpretation of illness in a number of studies (Fleer *et al.* 2006, Bussing and Fischer 2009). However, Skaali *et al.* (2009) found that lower levels of education were significantly associated with higher levels of fear of recurrence, whilst women with higher educational attainment reported more triggers that remind them of cancer in Gil *et al.*'s (2004) study. Also, in terms of determinants of benefit-finding, the only significant socio-demographic factor in Jansen *et al.*'s (2011) study was education. Those with high levels of educational attainment reported moderate to high levels of benefit-finding less often (Jansen *et al.* 2011). The pattern was similar for post-traumatic growth, but the relationship was not significant. They suggested that a possible explanation as to why those with higher educational attainment experienced less benefit-finding and post-traumatic growth was that, taking lower education as a proxy for lower socioeconomic status, those with lower socioeconomic status may experience more hardship in their lives 'thus may be more experienced in finding something positive from negative events' (Jansen *et al.*, 2011: 1161).

Fleer *et al.* (2006) found a sense of meaningfulness was associated with whether testicular cancer survivors were working. However, Dirksen (1995) found employment and income had no significant correlation with searching for meaning after a diagnosis of malignant melanoma. Income was also not strongly correlated with the impact of cervical cancer, or life changes, reported in Greenwald and McCorkle's (2007) study.

Ethnicity

Very few studies have explored the impact of ethnicity on the long-term cancer experience. One, by Foley *et al.* (2006), explored the impact of cancer type, age, gender and ethnicity on the cancer experience. Ethnicity was not associated with any of the themes identified ('That's life', 'Personal growth', 'Resentment' and 'Relinquishing control').

Cancer-related variables

Stage at diagnosis

Stage at diagnosis was not strongly correlated with the impact of cervical cancer or life changes reported in Greenwald and McCorkle's (2007) study, but Jansen *et al.* (2011) found that post-traumatic growth increased significantly with stage of diagnosis of colorectal cancer.

Cancer-type

Most of the studies in this review focused on one cancer type. However, comparative studies have reported contradictory findings regarding the impact of cancer type on the experience of cancer survivorship, and the meaning survivors find in the illness experience. For example, men with prostate cancer are more likely to identify themselves as survivors, compared to individuals with breast or colorectal cancer (Deimling *et al.* 2007). Cancer-type also influences the interpretation of illness. Breast cancer survivors had significantly higher ratings of 'value'²⁰ than colorectal or ovarian cancer survivors in Bussing and Fischer's (2009) study. However, other studies have found that cancer type is not associated with the impact of disease (Foley *et al.* 2006, Zebrack *et al.* 2008).

²⁰ Gaining value from the illness experience.

Time since diagnosis/treatment

In the main, studies have reported that the number of years since diagnosis/treatment does not impact the experience of, meaning ascribed to, or interpretation of cancer (Dirksen, 1995; Flerer *et al.*, 2006; Bussing and Fischer, 2009). Yet Die-Trill (2000) suggested that causal thinking is associated with time since diagnosis. Those diagnosed more recently are more likely to report causal attributions, possibly because the intensity of the situation initiates such thinking (Die-Trill 2000). However, this contradicts other research which suggests that the meaning of illness is more apparent later on, when survivors have had time to process what has happened to them (Mathieson and Stam 1995, Bowman *et al.* 2003).

Studies suggest that fear of recurrence is not necessarily related to time since diagnosis and treatment (Gil *et al.* 2004, Skaali *et al.* 2009, Hubbard and Forbat 2012). Gil *et al.*'s (2004) study on women with breast cancer found that time since diagnosis was not significantly related to the average number of triggers experienced that remind survivors of cancer, suggesting that uncertainty and fear of recurrence do not diminish over time (Gil *et al.* 2004).

Cancer treatment and symptoms

Deimling *et al.* (2007) found that reduction or cessation of symptoms or effects of treatment and successful treatment played a role in encouraging identification as a cancer survivor. Conversely, experiencing a greater number of symptoms was associated with identifying as a cancer patient. Receiving a greater number of treatments was weakly associated with adopting the survivor identity, as was having chemotherapy (Deimling *et al.* 2007). However, conversely, survivor centrality was not related to cancer variables regarding treatment or prognosis in a study of long-term breast cancer survivors (Helgeson 2011).

Lelorain *et al.* (2010) found that medical and demographic variables were poor predictors of post-traumatic growth in long-term breast cancer survivors. Only chemotherapy was a predictor of growth, but it was not significant in regression analyses. They suggested these results are in line with previous research that has demonstrated a relationship between perceived seriousness of cancer (for which chemotherapy could be an indicator) and growth. Indeed, post-traumatic growth was positively associated with treatment with chemotherapy in Jansen *et al.*'s (2011) study of colorectal cancer survivors.

Life stage/context

Carter (1993) emphasised the importance of context, and the individualised nature of the breast cancer experience: '...while there are many commonalities in surviving cancer, surviving is interpreted in view of each person's unique life context' (1993: 360). The phases of Carter's model of 'going through' cancer are interpreted within the context of individual background, sources of meaning and models of understanding illness: 'The illumination of context sheds light on the diverse interpretations and possibilities that are embedded in going through the cancer experience. Informants' stories showed how disease and illness interpretations make sense within the context of their lives' (1993: 357). Shapiro *et al.* (1997) also highlighted a need to explore life stage, recent crises, and available support when exploring the impact of cancer on identity. Some people may be more or less 'psychologically vulnerable' to the cancer experience due to previous life experiences (1997: 551). Therefore, there is a need to understand identity and meaning within the context of individuals' lives (Shapiro *et al.* 1997).

Fleer *et al.* (2006) found a sense of meaningfulness was weaker in testicular cancer survivors who had experienced more negative life events, whilst

women diagnosed with breast cancer, who stated that their satisfaction with life was high, reported higher levels of post-traumatic growth than women with low life satisfaction (Mols *et al.* 2009b). It also appears that suffering other co-morbidities impacts the cancer experience. Fleer *et al.* (2006) found testicular cancer survivors with another chronic disease experienced less meaning in life, whilst Zebrack *et al.* (2008) reported that survivors with more health problems experienced a negative impact of cancer.

Summary

This section of the review has highlighted the contradictory nature of findings pertaining to the influence of socio-demographic and cancer-related variables and life events on the illness experience during long-term cancer survivorship. The variability in findings points to a need for further research exploring the context of peoples' experiences in order to gain a better understanding of the meaning of cancer during this phase of the survivorship trajectory.

Critique of existing long-term survivorship research

The review identified several limitations to existing survivorship research.

Lack of definitional clarity

As already discussed in Chapter 2, the concept of cancer survivorship and, in particular, *who* is defined as a 'cancer survivor', is conceptually unclear. Some researchers did not specify what they meant by a 'cancer survivor', perhaps assuming that as the term is ubiquitous the reader knows who they were referring to. Various terms, many of which were not adequately defined, were used to describe individuals included in study samples. Terms included: 'post-illness' (Arrington 2003), 'living with cancer' (Colyer 1996, Hughes *et al.* 2009)

and 'in remission' (Persson and Hallberg 2004). Research was excluded from the review if it was unclear how many years the participants were post-diagnosis or treatment. This meant that potentially illuminating findings were not included for review because it was not possible to ascertain if the sample comprised long-term survivors or not.

There was also a lack of definitional clarity regarding terminology used to highlight the growth and transformation experienced by some long-term survivors. Thornton (2002) acknowledges that it is difficult to synthesise literature on the positive changes associated with a cancer diagnosis as there is such definitional variability. Terms used in studies include: positive changes, benefit-construal, benefit-finding, post-traumatic growth, thriving, finding meaning and resilience. Only a small number of studies provided clarity of definition, for example, distinguishing between post-traumatic growth and benefit-finding (Mols *et al.* 2009b, Jansen *et al.* 2011).

Limited research on the subjective experience of long-term survivorship

In comparison to research conducted on experiences of diagnosis and treatment, and the transition period following treatment, little research has explored the experience of long-term cancer survivorship. This gap in the evidence base has been highlighted by researchers who argue that research on experiences of long-term survivorship is needed, particularly as survival rates continue to improve, and people survive cancer for longer (Pedro 2001, Aziz 2002, Aziz 2007, Deimling *et al.* 2007, Aziz 2009, Richardson *et al.* 2009, Richardson *et al.* 2011).

The main focus of the majority of the identified research was on searching for meaning in the cancer experience. Several studies focused on positive growth and transformation in the aftermath of cancer. However, as already discussed, more recently, researchers have argued that a more balanced

approach to exploring the meaning of cancer should be taken, to account for the negative, as well as positive, changes that can occur during long-term survivorship (Bishop *et al.* 2011, Kahana *et al.* 2011, Schroevers *et al.* 2011). A smaller body of research focused specifically on the impact of cancer on self, including adoption or rejection of the 'survivor' identity, and relationships during long-term survivorship. Only one paper was found that specifically explored the impact of cancer on interpersonal relationships during the long-term survivorship phase. Thornton and Perez (2007) highlight that most of the studies on relationships focus on patients actively involved in treatment. Therefore 'it is not clear if the same processes apply to long-term survivors, or how relationship processes and interaction patterns evolve over time as the individual transitions into long-term survivorship' (2007: 203).

Limitations to research on the experience of long-term cancer survivorship

Of the forty-three papers included for review, twenty-one adopted a quantitative design, the majority of which were cross-sectional surveys using a variety of validated and researcher-constructed instruments (See Table 3.2). Twenty reported the use of qualitative methods (predominantly in-depth or semi-structured interviews) and two studies used mixed methods. Qualitative methods were generally employed in studies exploring the impact of cancer on identity and relationships. A common criticism of psycho-oncology research is the prevalence of research on women with breast cancer (Fleer *et al.* 2006, Harrop *et al.* 2011). Over half of the papers identified in this review were on breast cancer survivors, or the majority of the sample was breast cancer survivors. Samples were also ethnically and culturally homogeneous - predominantly White, middle-class women. This is another common criticism of research conducted in this field. Two thirds of the papers were written on research conducted in North America, with only three papers from the UK. These figures clearly highlight the dearth of research on issues facing long-term survivors in the UK. Essentially, methodological limitations, such as the

majority of studies being based on one cancer type (breast), and the use of a wide range of standardised and researcher-generated instruments, limit our ability to compare study findings and draw conclusions about how, when and why people thrive or struggle in the aftermath of cancer.

It has been highlighted that studies often include survivors who span different survivorship phases (Schroevers *et al.* 2006, Bellury *et al.* 2011). If, as suggested, the experience of cancer is dynamic and changes over time (Pelusi 1997, Bowman *et al.* 2003), it is important to distinguish between the different phases of survivorship in the analysis. Just over half of the papers included for review were specifically on survivors who were five years or more post-diagnosis/treatment. The remainder spanned survivorship phases (although the mean time since diagnosis/treatment was ≥ 5 years). Only a small number of these studies distinguished between those who were short or longer-term survivors, such as Rozmovits and Ziebland (2004) and Hubbard and Forbat (2012). If studies span survivorship phases, reports should distinguish between those phases to draw attention to potential similarities and/or differences in experience across the survivorship trajectory.

Research is rarely guided by theory

Only in a small number of papers did researchers specify that they were guided by a specific theoretical framework (See Table 3.2). More quantitative than qualitative studies were theory-driven. Theories guiding quantitative studies included: attribution theory (Dirksen 1995), Lazarus and Folkman's stress-coping framework (Lazarus and Folkman 1984, Bowman *et al.* 2003), Moos and Schaefer's (1993) conceptual model of stress and adaptation (Schroevers *et al.* 2006), identity theory (Mead 1934, Cooley 1964, Deimling *et al.* 2007) and Lipowski's meaning of illness categories (Lipowski 1970, Bussing and Fischer 2009). Several studies also appeared to be guided by Tedeschi and

Calhoun's theory of post-traumatic growth (Mols *et al.* 2009a, Lelorain *et al.* 2010, Jansen *et al.* 2011).

Theories guiding qualitative studies included Douglas' exploration of the physical and social body (Douglas 1984 (1966), Rozmovits and Ziebland 2004), Bury's biographical disruption (Bury 1982, Hubbard and Forbat 2012), quality of life (Ferrell *et al.* 1997, Dow *et al.* 1999), critical gerontology (Sinding and Gray 2004) and Danish life philosophy (Sekse *et al.* 2009). The use of theory in qualitative research has caused debate in the field (Bryman 1988, Silverman 2010). Bryman (1988) considers that 'prior specification of a theory tends to be disfavoured because of the possibility of introducing a premature closure on the issues to be investigated' (1988: 81). However, he also suggests that, in order to interpret data and draw conclusions, some degree of 'contextualist understanding, whereby the understanding of events and activities has to be grounded in the specific milieu being examined' (Bryman, 1988: 86) is often necessary. Future studies employing qualitative methods might consider adopting a relevant theoretical framework to underpin the study in order to move beyond description and facilitate understanding of the findings generated (Hubbard *et al.* 2010, Hubbard and Forbat 2012).

Justification for the focus on long-term survivorship

Long-term cancer survivors are a growing, yet under-researched part of the cancer survivorship trajectory (Aziz 2009). However, as this part of the review has demonstrated, the impact of cancer on survivors' outlook on life, identity and relationships continues to be felt during this phase of survivorship.

Bowman *et al.* (2003) argue that 'individuals' meaning of their illness experience changes over time and may not be explicit until long after treatment has been completed and they have been living with cancer for some time' (2003: 226). Indeed, Mathieson and Stam (1995) and Tomich and

Helgeson (2002) have argued that newly diagnosed patients are too concerned with diagnosis and treatment to consider the meaning of their experience at that time. However, later on, 'people may reflect on the meaning of the experience in their lives' (Tomich and Helgeson, 2002: 156) and 'the cumulative effect of the changes which result from the diagnosis lead to the individual's awareness that she has been transformed permanently in some way by having cancer' (Mathieson and Stam, 1995: 299). According to Bowman *et al.* 'the longer survivors live with cancer and encounter other life events, they may begin to incorporate it into their lives and regard it as part of their living experience' (2003: 228).

A systematic review of the current evidence base has identified priority areas for survivorship research in the UK including: identifying those at risk of ongoing problems, exploring the psychological and social impact of cancer and identifying the ongoing physical symptoms of cancer experienced as a result of treatment (Richardson *et al.* 2011). Richardson *et al.* (2011), like others before them, found that the majority of survivorship research has concentrated on the early phase of survivorship (Deimling *et al.* 2007, Aziz 2009). As the number of long-term survivors increases, 'it is critical that investigators make a commitment to understand the unique needs of long-term cancer survivors' (Aziz, 2009: 783).

Conclusions and next steps

For a minority, it appears that a diagnosis of cancer has relatively little impact, and 'normal' life resumes post-treatment. However, for others, cancer redefines who they are, profoundly affecting their outlook on life, identity and relationships, both positively and negatively. For these survivors, cancer is ongoing (Pelusi 1997, Sinding and Gray 2004) and often 'immediate and present' in their lives (Thomas-Maclean, 2005: 207). Taking account of the limitations to the existing evidence base, in particular, methodological and

conceptual variability, further research is needed to explore the experience of long-term cancer survivorship. This critical appraisal of the literature has demonstrated that there is relatively limited qualitative research exploring the experience of long-term survivorship (defined as ≥ 5 years post-treatment), guided by an established theoretical framework. With this in mind, Part 3 of the literature review explores the potential applicability of *liminality* as a framework for understanding experiences of long-term cancer survivorship.

Chapter 4. Literature Review: Part 3 - Liminality as a framework for understanding the experience of cancer survivorship²¹

Introduction

In the previous chapter, I described survivorship as a process of living with, through and beyond cancer (Lance-Armstrong-Foundation 2004). One approach that may facilitate our understanding of this process is van Gennep's (1960) 'rites of passage'. Specifically, the liminal phase of this ritual process is said to help us understand the transition between roles or positions in society (Van Gennep 1960, Turner 1967, Turner 1969). This part of the review describes van Gennep's rites of passage, in particular, the liminal phase. This is followed by a critical review of the application of liminality in cancer research, including a synthesis of research to date that has utilised liminality to explore the cancer experience. The aim of this chapter is to explore the utility and applicability of liminality for understanding experiences of long-term cancer survivorship.

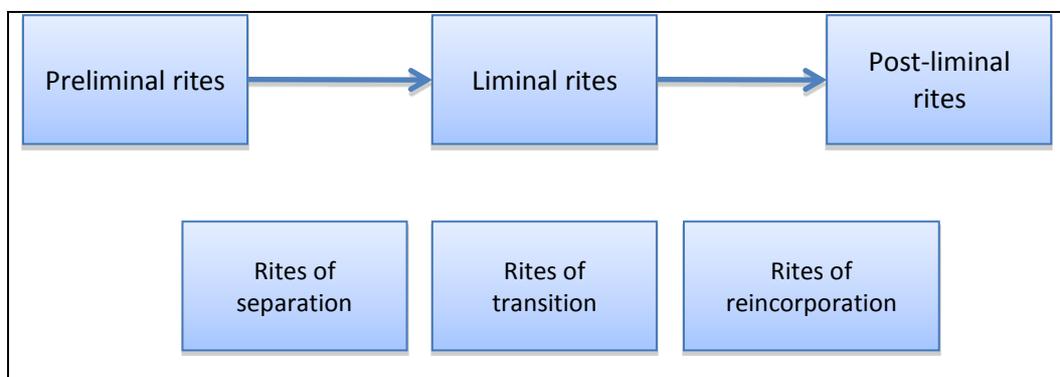
Theoretical context: rites of passage and liminality

The concept of liminality stems from the work of anthropologist van Gennep and, subsequently, Turner, on ritual and rites of passage (Van Gennep 1960, Turner 1967, Turner 1969). Van Gennep (1960: 3) suggested that 'the life of an individual in any society is a series of passages from one age to another and from one occupation to another'. Originally, the rites of passage model outlined a 'succession of initiatory scenarios, each of which has the effect of incorporating the individual or group of individuals concerned into a new

²¹ This chapter was the basis for a paper published during the course of the study: Blows *et al.* (2012) Liminality as a framework for understanding the experience of cancer survivorship: a literature review. *Journal of Advanced Nursing*, 68 (10) 2155-2164.

position within the social framework' (Grainger, 1974: 86). Typical rites include life events such as pregnancy, birth, marriage and death (Van Gennep 1960). As such, rites of passage occur when there is a transition in cultural expectations, social roles or status. The model assists in understanding that transition (Grainger 1974, Martin-McDonald and Biernoff 2002, Molzahn *et al.* 2008). Rites of passage can be divided into three stages (Figure 4.1): preliminal rites (rites of separation), liminal rites (rites of transition) and postliminal rites (rites of reincorporation). A rite of passage begins by 'severing connection' with a previous social state or position, followed by an ambiguous time where individuals find themselves 'in-between' social positions, and ends with 're-entry' or 'rebirth' into a new social position (Hockey 2002). The stages of the rites of passage are not experienced to the same extent by everyone, nor in all situations. For example, a funeral focuses on separation, whilst marriage centres on incorporation.

Figure 4.1: The rites of passage



(Source: van Gennep, 1960)

Van Gennep's rites of passage 'schema' (Hockey, 2002: 212) identified ways in which individuals moved between social locations which were often age-related e.g. single to married (Hockey, 2002). Hockey argues that van Gennep's 'schema' details the process of transition 'with the notion of passage encompassing an ambiguous zone which is betwixt and between fixed social positions' (2002: 213). The ritual and ceremony ensured these

transitions were regulated so that wider society was not harmed by them; therefore rites of passage had a *protective* function for society.

Van Gennep argues that differences lie in the detail – ‘the underlying arrangement is always the same. Beneath a multiplicity of forms, either consciously expressed or merely implied, a typical pattern always recurs: the pattern of the rites of passage’ (van Gennep, 1960: 191). He concludes that some transitional periods ‘acquire a certain autonomy’ (1960: 191-2). Of particular interest is van Gennep’s idea that in certain ceremonies the transition period is ‘sufficiently elaborated to constitute an independent state’ (van Gennep, 1960: 11) and therefore the rites of passage are ‘reduplicated’. He gives the example of betrothal, which is historically a liminal period between adolescence and marriage. However, the passage from adolescence to betrothal also includes a series of rites of separation, transition and incorporation, and the same from betrothal to marriage (Van Gennep 1960).

Turner built on van Gennep’s work in the 1960s with his study of Ndembu ritual in Zambia (Turner 1967, Turner 1969). His seminal work was *The Forest of Symbols* (1967) which included a paper entitled: *Betwixt and Between: the Liminal Period in Rites of Passage*. Turner asserted that rites of passage are not confined to a ‘ritual context’ and, therefore, are not restricted to movement between ‘ascribed’ statuses such as birth, marriage and death. He suggested that a rite of passage can also apply to entry into a ‘new achieved status’, for example, membership of a certain group (Turner 1967: 95).

Turner was particularly interested in the ‘sociocultural’ properties of the liminal (transition) period. He asserted that society comprises a ‘structure of positions’ but liminality is an ‘interstructural situation’ where culturally recognised positions, such as being married, single, an infant, etc. no longer apply (Turner, 1967: 93). Liminal people are structurally ‘invisible’ - they are ‘no longer classified and not yet classified’ (1967: 96), and therefore are ‘betwixt and between’ structural classification as ‘these persons elude or slip

through the network of classifications that normally locate states and positions in cultural space' (Turner, 1969: 95). As such, they are often described as being on the threshold, or margins of society (Froggatt 1997).

As highlighted, Turner argued that there is no structure or hierarchy in the liminal period. The emphasis is on equality and a collective mentality – 'a community of comrades' (Turner, 1967: 100). The community of liminal people is referred to as 'communitas' (Turner, 1969: 96). The hierarchy operating outside this community is often based around notions of obedience and passivity. Liminal people are 'linked by special ties which persist after the rites are over' (Turner, 1967: 101). 'Communitas' is considered 'anti-structure' and as such is 'hedged around' (Turner, 1969: 109) by wider society, which leads Turner to suggest that liminal people are perceived as 'dangerous, inauspicious' (1969: 108). Turner cited the work of Mary Douglas (1984 (1966)) to highlight this position. Douglas suggested 'recognition of anomaly leads to anxiety and from there to suppression or avoidance' (1984 (1966): 5).

Therefore, in terms of social structure, those in the liminal phase are effectively taken out of society to protect wider society. Turner highlights the 'juxtaposition of the central, transitional phase and the twin periods of separation and reintegration which provide its boundaries... He describes an opposition between the enduring rule-bound hierarchies of the familiar social world and the transitory unbounded nature of liminal time and space' (Hockey and James, 1993: 167). As individuals enter into a rite of passage 'they submit to a temporary loss of their social power and position' (1993: 167). Therefore, characteristics of liminality include marginality, outsiderhood and structural inferiority (Hockey and James 1993). Living in the liminal (or transition) period can therefore lead to negative feelings of 'ambiguity and paradox' (Turner 1967: 97).

Yet, Turner also suggested that transition could be transformative for those in the liminal stage, describing liminality as a 'stage of reflection' (1967: 105)

where 'the reformulation of old elements in new patterns' occurs (1967: 99), resulting in liminal people re-entering society at a higher social status. Individuals fall into limbo between past and present modes of daily existence, then return to everyday life at a higher level of status, consciousness or social position (Turner, 1977: 34). The liminal state is therefore one of 'potency and potentiality' (1977: 33-34) – 'a realm between what is and what may be' (Squier, 2004: 4). Likewise, liminality can also be a source of power. Turner argued that marginal individuals are often those that provide a critique of society, outsiders might have disruptive power from the perspective of those in the centre and as the structurally inferior 'are not pinned within the ranks and hierarchies of the powerful, their attributes are open to interpretation, potentially manipulable by those who find themselves in this role' (Hockey and James, 1993: 169). As such, Turner developed van Gennep's original conceptualisation of the rites of passage serving a protective function in society, to suggest that rites of passage also have a *creative* function - they can be transformative - and it is in the liminal stage where this occurs.

Summary

Turner emphasises the contrast between 'state' (a condition/position) and 'transition' (process). The rites of passage highlight the 'transition' between 'states'. A 'state' can be defined as a 'fixed or stable condition' (Turner, 1967: 93) but 'state' can also be applied to the 'physical, mental or emotional condition in which a person or group may be found at a particular time' (Turner, 1967: 94). In the liminal phase, the 'state' of the passenger is ambiguous - liminal or 'threshold people' are ambiguous because they are in-between states/positions. 'Transition' is the *process* of transformation from one 'state' to another. Being 'on the threshold' or in-between states/positions is a feature of social structure (Van Gennep 1960). According to Froggatt (1997: 125) 'the transition stage is both a threshold or boundary as well as a "space" in its own right and the time (and place) where the people passing

through the rite are cut off from the wider structure of society, in a temporary, marginal position'. Turner concluded that 'life experience contains alternating exposure to structure and *communitas*, and to states and transitions' (1969: 97).

Applicability of the rites of passage model in contemporary society

Froggatt (1997) provides a contemporary critique of liminality in her paper on the applicability of the rites of passage model within hospice culture. She suggests the critique is warranted considering van Gennep's rites of passage was first published in 1908 and based on traditional (small-scale tribal) societies. Froggatt's main issue focuses on the different contexts and perspectives that exist in today's society, and whether a model developed over a century ago can still be relevant. Transitions within the life-cycle still exist, in particular with respect to health and sickness, and life and death but, as Squier (2004) asserts, today, these transitions take place within the shifting context of biomedicine. Whilst van Gennep's model was based on a traditional, Aboriginal society in Australia, Turner sought to understand the applicability of liminality in contemporary society. The liminal phase is now applied in situations that go beyond purely ritual context e.g. categories of experience (Froggatt 1997).

Based on van Gennep's assertion, it is assumed that ritual 'ameliorates the conflict between the individual and society and maintains the social order' (Froggatt, 1997: 126) – the protective function of the rites of passage. However, when van Gennep proposed his rites of passage model, the society he was studying was more homogeneous than the world today; today we have a 'variety of lifestyles and a tolerance for diversity' (Froggatt, 1997: 126). Therefore, it could be said that, in 'Western' society, it is not always the case that what is 'unclear is unclean' (Douglas 1984 (1966)) and that the protective function of the rites of passage is no longer as relevant. However, Froggatt

concludes that there is a place for the rites of passage, as transitions in the life cycle still exist, just within the 'diverse cultural contexts of contemporary society' (1997: 126). Therefore, whilst the notion of a 'generalised ritual form has been rightly questioned... ritual still exists despite recognition of the variety of perspectives which may coexist within society' (1997: 126). What is important is to recognise those differences. Indeed, Froggatt (1997) argues the social context of the ritual needs to be acknowledged if its wider effects are to be illuminated i.e. the focus should not be on the individual in isolation but the effect of transition within their social world.

Squier (2004: 5) suggests that we need a revision of Turner's 'predominantly cultural definition' of liminality. Squier believes that liminality is now a 'biocultural' state due to advances in biotechnology, which mean the boundaries we cross over are no longer stable. These biomedical changes have social and political implications. Turner's liminality lies on the assumption that, 'while the liminal is shifting, life is still stable' (Squier, 2004: 6). However, technological and medical developments mean that is not always the case today; the boundaries of human existence have become blurred. Life and death are not what they once were. Biological limits are being stretched due to biomedical intervention: 'the old notion that the form and trajectory of any human life have certain inherent biological limits, and the new notion that both the form and trajectory of our lives can be reshaped' (Squier, 2004: 9).

Squier (2004: 273) states that 'the anthropological definition of liminality is generally restricted to cultural modes of negotiating life passages' e.g. the rituals to mark the facts of human life e.g. birth, puberty, marriage, death. However, in today's society, this definition 'fails to represent the complex ways that culture intervenes in and produces nature' (2004: 274). Biomedicine/biotechnology means that where once life had beginnings and ends that were established, they are now subject to 'biomedical

manipulation' (Squier 2004). As such, those beginnings and endings are not stable, but fluid.

Taking cancer as an example, the impact of a cancer diagnosis on the individual will, in part, be determined by other peoples' reactions to that diagnosis. Today, how individuals are perceived is changing as a result of shifting understandings of cancer in society. Medical advancements in cancer screening and treatment mean that what was once a death sentence is now a disease that many can survive. If a person diagnosed with cancer 'reincorporates into a state of health, it sends a welcome message to wider society that they are 'cured' and therefore are no longer an "omen of hazard"' (McKenzie and Crouch 2004). If the cause of cancer is unknown or if the individual experiences ongoing consequences of cancer treatment (for example, they look or act differently – have lost their breast, have no hair, their bodily functions have been compromised) this perhaps sends a different message – that what is unclear is unclear (Douglas 1984 (1966)). There is no one outcome like rituals of birth, marriage, death, etc. but diversity of outcomes that have to be positioned within their wider social context if we are to understand them.

The next section explores how the rites of passage and liminality have been applied to the illness experience more broadly and the cancer experience specifically.

Application of the rites of passage and liminality to the cancer experience

Rites of passage and the illness experience

The rites of passage and, in particular, liminality, have been utilised to explore the illness experience, including kidney dialysis and transplantation (Martin-

McDonald and Biernoff 2002, Crowley-Matoka 2005, Molzahn *et al.* 2008), HIV/AIDS (Bloom 1997), Hepatitis C (Treloar and Rhodes 2009), chronic pain (Jackson 2005), Alzheimer's (Shomaker 1989), infertility (Allan 2007), those living in a permanent coma (Kaufman 2000), as well as the experience of disability (Murphy *et al.* 1988, Harrison and Kahn 2004) and hospice culture (Froggatt 1997).

The applicability of the rites of passage is outlined by Martin-McDonald and Biernoff (2002: 347) who argue that 'moving from the realm of health to that of illness crosses over boundaries that alter the social position of a person'. Molzahn *et al.* (2008: 15) go on to suggest 'liminality refers to the ambiguous experience of one's life story being disrupted through illness'. This can lead to uncertainty and ambiguity with regard to self-identity because people find themselves in in-between and ambiguous spaces, which can result in social indefiniteness and isolation (Mwaria 1990, Molzahn *et al.* 2008).

Review of research on the liminality and the cancer experience

A narrative review was undertaken, to provide a comprehensive overview of the topic. Using a textual narrative approach (Lucas *et al.* 2007, Barnett-Page and Thomas 2009), I arranged studies into homogeneous groups – by stage of the cancer trajectory. An alternative approach would have been a thematic synthesis, organising findings by descriptive theme. Whilst synthesising findings under descriptive themes would have highlighted facets of the liminal experience, it would not have allowed me to explore the utility of the liminality at different stages of the cancer trajectory. Indeed, the textual narrative approach is useful when the aim is to identify the scope of what has been studied, and gaps that need to be addressed (Lucas *et al.* 2007).

Search strategy and outcome

Electronic searches of Medline, PsycInfo, British Nursing Index, Cinahl, ASSIA, Web of Science, Cochrane Library and British Library online databases were conducted in November 2009 and updated in September 2011. The search terms were: cancer AND liminal* OR rite* of passage. Databases were searched for publications in English, covering the period 1985 to 2011. In addition, reference lists of relevant literature were reviewed to identify further pertinent studies. Table 4.1 outlines the broad inclusion and exclusion criteria applied to the fifty papers identified. As a result, ten studies were included for review (Table 4.2). Due to the small number of studies identified, a decision was made to include all studies that used the rites of passage model or liminality to explore the cancer experience. As per the textual narrative approach, to identify the strength of evidence presented, a critique of the studies was included as part of the review (Lucas *et al.* 2007).

Table 4.1: Liminality search inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Individuals affected by primary cancer in adulthood (18+ years)	Childhood cancers
Any stage of the cancer trajectory	Adult cancer survivors diagnosed in childhood
Utilises van Gennep's rites of passage model/Turner's liminality, or developments of these concepts, as an analytical framework or draws on the theory in discussion	Experiences of partners/family members/those close to the cancer survivor

Studies were arranged according to participants' stage of the cancer trajectory: cancer risk, treatment, post-treatment and studies including survivors at various points of the cancer trajectory. Study characteristics, context and findings were reported, as well as how liminality was employed, to highlight facets of the liminal experience at various stages of the trajectory.

Liminality and the experience of cancer

The concept of liminality was used in three studies on cancer risk (Luxford 2003, Forss *et al.* 2004, Scott *et al.* 2005), two studies on men undergoing hormone therapy for prostate cancer (Navon and Morag 2004, Gray *et al.* 2005), two studies on experiences of cancer patients at various points in the cancer trajectory (diagnosis, treatment and post-treatment) (Little *et al.* 1998, Thompson 2007), one longitudinal study exploring the experience of cancer over time (Cayless *et al.* 2010) and two studies on experiences post-treatment (Crouch and McKenzie 2000, McKenzie 2004). Liminality was employed as an explanatory framework at the outset in four studies (Forss *et al.* 2004, Navon and Morag 2004, Thompson 2007, Cayless *et al.* 2010). Of the remaining six, researchers concluded during the analysis and/or discussion that liminality was a relevant means of conceptualising the cancer experience (Little *et al.* 1998, Crouch and McKenzie 2000, Luxford 2003, McKenzie 2004, Gray *et al.* 2005, Scott *et al.* 2005).

Experiences of those 'at risk' of cancer

Luxford (2003) examined the experience of older women being diagnosed with benign breast disease through a case study developed after an in-depth interview with 'Alice'. Being diagnosed with benign breast disease resulted in Alice living with what Luxford referred to as 'troublesome breasts'. Alice described a perceived increased risk, and subsequent fear, of developing breast cancer, leading to feelings of uncertainty and vulnerability. Alice 'was not sure whether she was healthy or ill' (2003: 149) leading Luxford to describe Alice as living in a liminal state of 'health-but-not-health' (2003: 153).

Similarly, Forss *et al.* (2004) conducted a phenomenological hermeneutical analysis of women's experiences of an abnormal Pap smear test in Sweden. The Pap smear can detect cervical cancer or identify those at risk of

developing the disease. The authors argued that screening programmes may lead to 'new kinds of sickness experiences' as results can render an individual between sickness and health, occupying an 'at risk' state (2004: 309). Forss *et al.* explored this 'at risk' state, guided by the concept of liminality. They suggested that women go for a smear test assuming the result will be normal and that they are confirmed as 'healthy'. However, an abnormal result, where neither health nor disease is confirmed, creates a sense ambiguity. The woman is deemed 'potentially unhealthy' which is interpreted as an 'unintentional transition from confirmation of health to liminality' (Forss *et al.* 2004: 318). Women experience liminality 'biomedically, organisationally and experientially' (2004: 318). Biomedically, neither normality nor disease is confirmed. Organisationally, the individual does not belong in the context of health or disease/treatment. Experientially, the abnormal result creates uncertainty and ambiguity, as the women expect to be told they are healthy.

The last paper reported a UK study on how users of a cancer genetics service make sense of their genetic risk estimate and integrate it into their lives (Scott *et al.* 2005). Semi-structured interviews were conducted with 'clients' who had been referred to the service. Scott *et al.* described a shift in focus 'from the actual to the potential presence of disease' which created a new category of 'being-at-risk' and subsequent new social identity (2005: 1870). This position, as described in Forss *et al.*'s study, results in the individual occupying a unique position in the healthcare system as they are situated in 'a netherworld between healthy and the afflicted' (2005: 1870), occupying a 'potential "sick role"' (2005: 1872) not dissimilar to Forss *et al.*'s 'potentially unhealthy'. Their status is unclear and ambiguous and, as a result, they are 'denied access to the privileges of both the unwell and the healthy' (Scott *et al.* 2005: 1872).

Table 4.2: Liminality papers included for review

Author(s)	Year	Country	Cancer-type	Survivorship phase	Aims	Methods	Sample
Luxford	2003	Australia	Benign breast disease	Pre-cancer	Explore how the experience of benign breast disease and risk disrupts relationship with self/body	Qualitative – discursive analysis and case study	n=1
Forss <i>et al.</i>	2004	Sweden	Cervical cancer	Pre-cancer (screening)	Explore the experience of receiving notification of an abnormal smear result	Qualitative - open-ended interviews	n=30
Scott <i>et al.</i>	2005	UK	Users of cancer genetics service	Pre-cancer (screening)	Explore how people deemed at familial risk of cancer integrate that knowledge into their lives	Qualitative - semi-structured interviews	n=58
Navon & Morag	2004	Israel	Prostate	Treatment	Explore the disruption experienced following hormone therapy for advanced prostate cancer	Qualitative - in-depth interviews	n=15
Gray <i>et al.</i>	2005	Canada	Prostate	Treatment	Explore men's experiences of receiving ADT, how hormone therapy affected identity	Qualitative - open-ended interviews	n=12
Little <i>et al.</i>	1998	Australia	Colorectal	Diagnosis – long-term survivorship	Explore the subjective experience of cancer	Qualitative - narrative interviews	n=10

Author(s)	Year	Country	Cancer-type	Survivorship phase	Aims	Methods	Sample
Thompson	2007	USA	Ovarian	Diagnosis - early survivorship (Up to 2 years post-diagnosis)	Explore the applicability of liminality to describe the experience of ovarian cancer survivors	Qualitative, semi-structured interviews	n=9
Cayless <i>et al.</i>	2010	UK	Prostate	Diagnosis – 1 year post-diagnosis	Explore applicability of liminality & biographical disruption to explain experiences of prostate cancer	Qualitative, longitudinal study. Semi-structured interviews	n=66
Crouch & McKenzie	2000	Australia	Breast	Post-treatment: 2 to 20 years post-treatment	Explore experiences of social interaction post-mastectomy	Qualitative, in-depth interviews	n= 7
McKenzie	2004	Australia	Various	Post-treatment – at least 2 years post-diagnosis	Explore the impact fear of recurrence (on the part of the survivor) and fear of cancer (on the part of those close to them) has on social interaction.	Qualitative, in-depth interviews	n=15

Experiences of hormone therapy

Navon and Morag (2004) investigated the impact of hormone therapy on advanced prostate cancer patients in Israel by conducting a qualitative study with fifteen men receiving treatment. They found that the men live an ambiguous existence, highlighted by a series of contradictions, which leads to 'biographical disruption' (Bury 1982). For example, hormone therapy allowed these men to recover, but without a corresponding sense of wellbeing. They still have a 'basic masculine self-identification', but this is countered by 'bodily feminisation' such as developing breasts and hot flushes. The authors concluded that 'concurrent contradictory processes of normalisation and deviantisation have subjected [these men] to a state of liminality' which leads to 'difficulty in classifying themselves into culturally available categories of able-bodiedness, sex, gender, marital status and social membership that normally produce the sense of identity' (Navon and Morag, 2004: 2343). Navon and Morag suggested that the gap between 'normal' and 'deviant' experiences widens over time; reinforcing the unclassifiability of these men and cementing their liminal status to the extent that participants feel they are 'not temporarily unclassified but permanently unclassifiable' (2004: 2344).

Gray *et al.* (2005) also conducted a qualitative study exploring experiences of twelve men receiving androgen deprivation therapy (ADT) for prostate cancer, and its impact on identity. As reported in Navon and Morag's study, Gray *et al.* suggested that ADT has the potential to threaten men's gender identity, with side effects of treatment such as hot flushes and developing breasts bringing them 'into the orbit of women's experience' (2005: 2761). Gray *et al.* explored how this could be construed as 'liminal', as men find themselves 'straddled between the two categories of gender' (2005: 2762). However, men refuse this liminality, either because they feel their sense of masculinity has not changed as a result of treatment or because they seek to retain a strong sense of masculinity (taking part in sports, doing physical work, etc.)

Yet, maintaining a strong sense of masculine identity is difficult for those who perceive an association between masculinity and sexual function. Men spoke of the impact ADT has on their sexuality, including loss of libido and erectile dysfunction. Gray *et al.* concluded that this, alongside a lack of suitable sexual rehabilitation interventions, 'make it difficult to adequately support men's desire to remain masculine' (2005: 2762), thus rendering them liminal.

Experiences across the cancer trajectory

Little *et al.* (1998) undertook narrative interviews with ten colorectal cancer patients, three months to twelve years post-colectomy, and concluded that liminality is a useful concept to describe the cancer experience of these patients. However, their conceptualisation of liminality differs to that of van Gennep's rites of passage model. The uncertainty and possibility of cancer recurrence means individuals are effectively trapped between two social states: health and illness (Little *et al.* 1998). As a result, individuals with cancer enter a state of liminality that persists for the rest of their life. Little *et al.* suggested liminality is experienced in two phases: 'acute' and 'sustained'. 'Acute' liminality begins at diagnosis and is characterised by disorientation, loss of control and uncertainty. 'Sustained' liminality follows the acute phase after an indeterminate period of time and is an 'adaptive, enduring phase' characterised by a search for meaning and challenges to identity (1998: 1492).

Little *et al.* (1998) also identified three themes that represent the subjective experience of these colorectal cancer patients: 'cancer patientness', 'communicative alienation from social familiars', and 'boundedness'. They argued that these 'elements' also encompass experiences of liminality. Little *et al.* (1998) suggested all three 'elements' are evident across the cancer trajectory but their salience varies in relation to time since diagnosis. 'Cancer patientness' refers to the 'persistent identification' as a cancer patient, regardless of time since treatment (Little *et al.* 1998: 1486). However, some

individuals 'go out of their way to deny any sense of cancer patientness' (1998: 1487). 'Communicative alienation' occurs when individuals with cancer are unable to communicate the nature of their experience to those close to them, because they have not been through the experience themselves (Little *et al.* 1998). Also, a sense of isolation is sometimes felt by cancer patients, as a result of social expectations placed on them to get 'back to normal' after treatment (Little *et al.* 1998). The inability to share experiences with those close to them means 'most patients recognised...[they] could only relate directly and with belief to those who had undergone similar experiences' (Little *et al.* 1998: 1489). The element of 'boundedness' refers to how the individual's social world 'contracts' through awareness of limits to space, time, power and social functioning as a result of cancer (Little *et al.* 1998). Survivors may experience a greater awareness of their own mortality, which instils a sense of uncertainty about the future (1998: 1488).

Thompson (2007) conducted interviews with nine women living with stage three ovarian cancer, the majority of whom had been diagnosed within the previous two years. She applied the concept of liminality as described by Little *et al.* (1998) to explore whether it reflected the experience of women with ovarian cancer. Overall, Thompson's findings supported the assertion that the cancer experience is a liminal one. However, she suggested a different kind of liminal experience to that described by Little *et al.* (1998), arguing that 'the liminal experience was often generative in nature, rather than being solely limiting or constricting' (2007: 345). Thompson reported how women in her study 'used a liminal experience differently' (2007: 346). In particular, the element of 'boundedness' was interpreted differently, with Thompson highlighting how, in contrast to Little *et al.*'s sense of 'boundedness', which implies limits, 'boundedness' can 'catapult an individual into meaningful positive change' (Thompson 2007: 346). To this extent, Thompson's findings fit more closely with van Gennep and Turner's original theorisations of liminality as part of a process of transformation.

Thompson reported two forms of 'communicative alienation'. The first related to women's inability to share their experiences with those close to them, because those close to them had not been through something similar (as per Little *et al.*'s conceptualisation). The second related to an inability on the part of the survivor to articulate their experiences due to the emotional and physical impact of treatment (Thompson 2007). Adding to Little *et al.*'s work, Thompson reported that women can only articulate their experiences if they have a receptive person to communicate with. Therefore, to overcome this 'communicative alienation', they actively seek out other women with ovarian cancer whom they perceive have a 'capacity to hear as well as provide recognition' (2007: 347). Whilst this finding is important, it also highlights a limitation to Thompson's study. Women were recruited to the study via support groups, which could imply a predisposition to seeking this type of support. Thompson (2007) barely touched on the element of 'cancer patientness', only briefly alluding to the fact that women did not identify themselves as cancer survivors. She concluded by agreeing with Little *et al.*'s assertion that the liminal state is a permanent one.

Changing experiences of cancer over time

Cayless *et al.* (2010) explored the utility of the concepts of liminality and biographical disruption (Bury 1982) to understand men's experience of prostate cancer over the first year of illness. Ten men included in this longitudinal, qualitative study were interviewed at three time points: at diagnosis, during treatment and in follow-up. Cayless *et al.* concluded, as did Navon and Morag (2004) and Gray *et al.* (2005), that prostate cancer causes disruption to men's masculine identity. In particular, the impact of physical side effects (on social life, body image, sexual function and relationships) and disruption to future plans influenced the level of disruption felt (Cayless *et al.* 2010). The 'betwixt and between' position of some of the participants was particularly evident in discussions regarding disrupted futures, with

uncertainty about the possibility of recurrence affecting forward planning. Even men with a good prognosis had concerns about whether cancer would return; this disrupted their future plans, resulting in uncertainty and ambiguity, and thus liminality (Cayless *et al.* 2010).

Post-treatment cancer survivorship

I identified two studies on experiences of survivors at least two years post-diagnosis (Crouch and McKenzie 2000, McKenzie 2004), drawn together in subsequent papers by the authors (McKenzie and Crouch 2004, Crouch and McKenzie 2006). The authors explored the impact cancer and fear of recurrence (on the part of the survivor) and fear of cancer (on the part of those close to them) has on social interaction.

McKenzie and Crouch highlighted the sense of separation survivors can feel from their social world as a result of being 'permanently branded by the disease' (2004: 140), exploring what they referred to as 'interpersonal emotional dissonance' (2004: 139) with respect to Bury's (1982) theory of biographical disruption and Little *et al.*'s (1998) concept of liminality. McKenzie and Crouch suggested survivors live in a world of 'dissonant interactions' (2004: 143) where they cannot express how they really feel, because of societal emphasis on turning away from death and a focus instead on positivity and uplifting stories about cancer. Survivors risk becoming the 'emotional carer', as they invest psychological effort to alter their feelings, remain positive and appear 'normal' to maintain close relationships and protect those close to them (McKenzie and Crouch 2004). However, due to the uncertainty created by the risk and fear of recurrence, which can leave cancer survivors 'profoundly occupied – even many years after diagnosis and treatment' (Crouch and McKenzie, 2006: 494), survivors find it difficult to maintain that positivity. This pretence leads to a 'mismatch' between the feelings of the survivor and their loved ones, which can lead to isolation and

leave survivors unable to share their existential concerns (Crouch and McKenzie 2006).

In McKenzie and Crouch's research, liminality emerged as a pertinent framework, providing insights into the ways in which survivors find themselves 'on the margins of everyday life' (2004: 141): 'Confined to a borderline condition between well and unwell, surviving and being threatened, cancer survivors must endure the indeterminacy of both their lives and their social personae. It is from in this liminal space that our respondents interact with their social environment' (Crouch and McKenzie, 2006: 494). Through their analysis, Crouch and McKenzie (2006) offered new insights into Little *et al.*'s (1998) liminality, suggesting survivors may experience three liminal phases, not just the two ('acute' and 'sustained') put forward by Little *et al.* (1998). The third phase begins five years or more post-diagnosis (i.e. long-term survivorship), 'transcending' 'sustained' liminality (Crouch and McKenzie, 2006: 495). It is during this third phase that survivors experience 'some security and become more like "ordinary people"' (2006: 495). Whilst not all survivors will reach this third stage, most 'yearn' for it 'and imagine themselves inhabiting a different state in the future' (2006: 495).

Discussion

This part of the review has presented an overview of van Gennep's rites of passage, in particular, the liminal phase. This was followed by a critical review of the application of liminality to the cancer experience, including a synthesis of research that has utilised liminality to explore the cancer experience. The aim was to bring together research that has utilised, or drawn upon, liminality, in order to explore its utility and applicability for understanding experiences of long-term cancer survivorship.

The rites of passage model has developed from van Gennep's focus on the ritual and ceremony of age-related transitions in traditional societies to Turner's contemporary understanding of an individual's movement into a newly ascribed status, state or level of consciousness. The liminal phase is now applied in situations that go beyond purely ritual context. Societies are more complex today, and diversity of context must be considered if we are to understand contemporary liminal beings.

However, broadly speaking, in the liminal phase, people find themselves 'betwixt and between the normal, day to day cultural and social states' (Turner, 1979: 94 cited in Little *et al.*, 1998: 1490). Being on the threshold, or margins, of society can lead to 'ambiguity and paradox' (Turner, 1967: 97). Indeed, the studies reviewed here highlight the contradiction and uncertainty felt by those living at different stages of the cancer trajectory, particularly diagnosis and treatment ('living with' cancer) and the period following completion of active treatment ('living through' cancer).

Little *et al.* (1998) sought to develop Turner's conceptualisation further, delineating 'elements' of the liminal experience in the context of cancer. These elements have been supported, to some extent, by Thompson (2007). Little *et al.* (1998) also argue that the liminal state is a permanent one - that individuals live in a state of 'sustained' liminality that persists until the end-of-life. This is in contrast to van Gennep's (1960) original 'rites of passage' model where those in the liminal phase ultimately transition out (reincorporate) into a higher social status. Whilst Navon and Morag (2004) and Thompson (2007) support Little *et al.*'s assertion, Crouch and McKenzie (2006) suggest a third phase that 'transcends' 'sustained' liminality and is experienced by long-term cancer survivors (those five years or more post-diagnosis). Crouch and McKenzie's conceptualisation is akin to van Gennep's original model, however, it appears to be somewhat aspirational for most long-term survivors as they 'yearn' to get back to normal, but may not reach this phase.

Perhaps, as Hockey and James (1993) have discussed with reference to elderly people, *marginality* might be a better term than liminality, as ‘unlike ritual liminars, marginals have no “cultural assurance of a final, stable resolution of their ambiguity”’ (Turner, 1974: 233 cited in Hockey and James, 1993: 133-134). Turner suggests that marginal individuals are simultaneously members of two or more groups whose social definitions and norms are distinct from, and often opposed to, one another. Marginal individuals use these groups in different ways: from one group they seek ‘unfettered emotional closeness (communitas)’ and the other they use as a ‘structural reference point’ (Hockey and James, 1993: 133). This could be the case for individuals living after a diagnosis of cancer. Their structural reference point is ‘health’ but they seek understanding from their communitas (others who are ‘potentially ill’).

Despite the apparent potential for liminality to facilitate our understanding of the cancer experience, the research presented has several limitations. Only a small number of studies have used liminality as a framework for understanding the cancer experience. Indeed, only four of the nine research teams explicitly employed liminality as an explanatory framework from the outset. Whilst a small body of evidence is emerging on experiences of breast and prostate cancer, other cancer-types generally do not feature in existing research. Only one study each on colorectal and ovarian cancer was identified, and studies that included a range of cancer types did not distinguish between them in the analysis. As such, we are limited in what can be said about the utility of liminality for exploring the experience of specific cancer-types.

Whilst research has explored liminality and the experience of living with, and through, cancer, research has not specifically explored experiences of living beyond cancer i.e. long-term survivorship (≥ 5 years post-diagnosis). Little *et al.* (1998), Crouch and McKenzie (2000) and McKenzie’s (2004) were the only researchers to include long-term survivors in their samples. In Little *et al.*’s study, survivors were between three months and twelve years post-

treatment, and in the Crouch and McKenzie (2000) and McKenzie (2004) studies, participants were between two and twenty years post-diagnosis. However, it is unclear how many of the participants were actually long-term survivors in these studies, as no breakdown of samples was presented. Whilst Little *et al.*'s (1998) analysis distinguished between those 'early in the illness episode' and 'late in the illness episode', what these phases represent in terms of time since diagnosis is unclear. As such, it is not possible to fully ascertain whether liminality is a pertinent framework for understanding experiences of long-term cancer survivorship.

Summary and conclusions

This review has demonstrated the utility of liminality as a framework for understanding the experience of living with, and through cancer (cancer risk, diagnosis, treatment and the period following the end of active treatment). However, gaps in the current evidence base mean that it is not possible to conclude that liminality is a pertinent framework for understanding experiences of long-term cancer survivorship. This being said, findings from studies including long-term survivors (Little *et al.* 1998, Crouch and McKenzie 2000, McKenzie 2004) suggest liminality does show utility and should therefore be explored further with this population.

Avenues for future research might include exploring whether Little *et al.*'s (1998) phase of 'sustained' liminality represents the experience of long-term cancer survivorship or whether there is evidence of a third phase of liminality, that begins around five years post-diagnosis, as suggested by McKenzie and Crouch (2004). Indeed, returning to the assertion that survivorship is a process, McKenzie and Crouch (2004) have suggested survivors return, or at least aspire, to some sense of normality. As liminality research has not *specifically* explored the experiences of long-term survivors, there is value in returning to van Gennep's original rites of passage model to explore whether

long-term survivors reincorporate into society, rather than stay permanently trapped in an ambiguous state between health and illness.

Further research to explore the salience of Little *et al.*'s (1998) 'elements' of liminality ('cancer patientness', 'communicative alienation' and 'boundedness') during long-term survivorship is recommended. Research is also needed to gain a greater understanding of what it is like to live in a state of liminality and the implications it may have in the context of survivors' daily lives, and their wider life course. Findings from several studies have suggested the overall notion of liminality can be construed quite negatively. Yet, Thompson (2007) argues that liminality can actually lead to positive action, as originally described by Turner (1967). Therefore, the implications of liminality, be they positive (generative, transformative) or negative (constraining), warrant further exploration.

Chapter 5. Methodology and Methods

Introduction

In this chapter I outline, and seek to justify, the approach taken to explore experiences of long-term cancer survivorship. I discuss the philosophical underpinnings of the study, data collection and analytical procedures, and issues pertaining to quality in qualitative research. I draw on methodological literature, as well as personal reflections on the research process.

Research objectives

The study aimed to meet the following objectives:

1. Describe the experience of long-term cancer survivorship
 - a. Explore how the concept of 'survivorship' has been constructed in relation to cancer, and what 'survivorship' means to those who are living five years or more post-treatment
 - b. Explore the impact of cancer on daily living, self, outlook on life and relationships (the illness experience)
2. Explore the utility of liminality as a framework for understanding the experience of long-term cancer survivorship
 - a. Does the state of 'sustained' liminality (Little *et al.* 1998) reflect the long-term cancer survivorship experience?
 - b. Do participants experience Little *et al.*'s (1998) 'elements' of:
 - i. 'Cancer patientness'
 - ii. 'Communicative alienation'
 - iii. 'Boundedness'

3. If participants live in a state of 'sustained' liminality, explore possible reasons for this. What differentiates those who live in a state of 'sustained' liminality from those who do not?

Summary of the research design

A multiple-case study design was adopted. Data were collected through an initial narrative interview with thirteen participants who were five years or more post-treatment for cancer, followed by a semi-structured follow-up interview. Semi-structured interviews were also held with some of the participants 'significant others'. Analysis took a holistic-content approach (Lieblich *et al.* 1998), underpinned by the three-dimensional narrative inquiry space (Clandinin and Connelly 2000). The 'restorying' of individual narratives (Creswell 2007) was followed by a cross-case analysis. This explored similarities and differences across cases to describe experiences of long-term survivorship at the aggregate level (Stake 1995, Stake 2006). Finally, moving beyond description, I explored the utility of liminality (Little *et al.* 1998) as a framework for understanding experiences of long-term survivorship.

Philosophical orientation

Interpretivism – realist vs. constructionist approaches

Interpretivists seek to understand human behaviour (Benton and Craib 2001). I adopted this epistemological approach in this study. Within the interpretivist paradigm, research methods are diverse but, essentially, there are realist and constructivist approaches (Elliott 2005). Both are concerned with understanding experience, but a realist approach asserts that the social world is 'out there' to be observed and described, whilst a constructivist approach

maintains that the social world is 'in the making' (Elliott, 2005: 18) and therefore there are multiple realities. This implies relativism, 'the belief that all points of view are context-dependent and of equal worth – and therefore there are no context-independent criteria by means of which we can judge between different points of view' (Benton and Craib, 2001: 185).

Hammersley argues that the realist-constructionist dichotomy is unhelpful. Realist ethnographers believe they are in the perfect position to discover the true nature of social reality as the methods they employ, such as participant observation, allow them to 'get closer to social reality' than other methods (2002: 66). However, constructionist ethnographers believe that people construct their social world 'both through their interpretations of it and through the actions based on those interpretations' (Hammersley, 2002: 67). People live in different social worlds and, as such, their worlds are 'incommensurable' i.e. one world cannot be treated as superior to, or truer than, another. Realists attempt to judge whether their findings are true or false with respect to a social reality that is independent of them, whilst constructionists accept there are multiple realities, none a truer representation than another. However, realism, in Hammersley's view 'abandons... one of the most valuable features of ethnography: its commitment to seeking to *understand* the perspectives of others, rather than simply judging them as true or false' (2002: 68). He argues that, given cultural and social context shapes our social realities, it is not possible to know whether findings are true or false. On the other hand, constructionism implies relativism, which leads to problems regarding how the validity of claims can be judged if all knowledge is said to be 'culturally relative' (2002: 71). Hammersley therefore proposes 'subtle realism' as an alternative to realism and constructionism/relativism. It is this perspective that I have adopted here.

Subtle realism

Subtle realism shares with realism the idea that there is a reality independent of our beliefs and understandings about it, but disagrees that we have direct access to that reality (Hammersley, 1992). It shares with constructionism that all knowledge is 'assumption-laden' and a 'human construction' (1992: 52). There are three elements to Hammersley's subtle realism. First, we can never be sure about the validity of any claims, however we can be 'reasonably confident' about the validity of claims based on judgements about their plausibility and credibility. Second, reality is independent of the claims social researchers make about it. Those claims may represent reality 'more or less accurately' (Hammersley, 2002: 73). Finally, there are multiple descriptions and explanations about the same phenomenon. The aim is to 'represent' reality not 'reproduce' it (1992: 51).

Therefore, Hammersley takes aspects of realism and constructionism in his development of subtle realism – as Snape and Spencer put it, he adopts a 'less extreme' take on these two positions (2003: 13). Hammersley takes from realism the idea that there is a reality 'out there' to be observed. However, he takes from relativism the idea that knowledge is a social construction, and there are multiple, 'non-contradictory' realities (Hammersley 1992, Hammersley 2002). The implications are such that because knowledge is based on cultural assumptions, 'we cannot legitimately claim that simply because we were "there" we "know"' (2002: 74-75). Hammersley is more concerned with how findings are used rather than whether accounts are true or false. However, if findings are to be used as a source of information about the phenomenon they refer to, issues of truth do become important. As it is my goal to inform practice and policy, issues pertaining to 'trustworthiness' of research are considered later in this chapter and in Chapter 10.

Study design - a multiple-case study

Case study research is a type of qualitative research strategy, as well as an object and product of research (Stake 2005, Creswell 2007). I took the approach outlined by Stake (1995, 2005) who draws on holistic and biographical research methods in case study research. Stake describes three types of case study: intrinsic, instrumental and multiple/collective case studies (Stake 1995, Stake 2005). For intrinsic case studies, the case itself is of interest. The purpose of conducting the case study is to gain a better understanding of that case. In contrast, an instrumental case study uses a case to explore a wider issue. As such, 'the case is of secondary interest, it plays a supportive role, and it facilitates our understanding of something else' (Stake, 2005: 445). A multiple case study extends this idea to several cases. I took a multiple case study approach, as I sought to understand participants' individual experiences, and then use their stories to explore long-term cancer survivorship more broadly (the 'quintain'²²). Taking Stake's conceptualisation further, I planned to adopt what Yin (2003) describes as an 'embedded' multiple-case study. Cases were to include more than one 'unit of analysis' (2003: 45) - the person who had been diagnosed with cancer and a nominated 'significant other'. However, in the event, it was not possible to construct embedded cases studies due to concerns regarding anonymity and confidentiality. These concerns are discussed later in this chapter.

Stake outlines the tension that exists regarding whether more attention should be paid to the 'pieces' i.e. the individual cases or the 'whole' i.e. the quintain. He refers to this as the 'case-quintain dilemma' (Stake, 2006: 1). He is concerned that 'sometimes a research question dealing only with the binding concept is developed, with occasional reference to individual cases.

²² 'The individual cases share a common characteristic or condition. The cases in the collection are somehow categorically bound together. They may be members of a group or examples of a phenomenon. Let us call this group, category, or phenomenon a "quintain"' (Stake, 2006: 4-6).

Such formalisation is likely to waste the special effort that has gone into a contextual, particularistic and experiential study' (Stake, 2006: 8) (and begs the question why one would conduct case study research in the first place). In this respect, the dilemma is that during cross-case analysis some of the specificity of the individual cases is lost, as there is inevitable synthesis of cases. This is actually a gain for the quintain, but highlights the case-quintain dilemma. Stake asserts that each case has its own context and background, which needs to be acknowledged. As such, part of the purpose of multiple-case research is to 'illuminate' some of these contexts (2006: 12).

The basic design of a multiple-case study, and the approach I took in this study, is to start with the quintain, study the specifics of the individual cases, interpret patterns *within* each case and then analyse similarities and differences *across* cases to develop "assertions" about the quintain (Stake 2006). The aim of multiple-case research is to understand the quintain.

Narrative inquiry

Case studies are often based on a wide variety of evidence, which means a range of data collection strategies can be employed to gather data (Stake 1995, Yin 2003, Stake 2005). Data used to develop the case studies in this study were collected using an initial narrative interview with those living long-term after a cancer diagnosis and a semi-structured follow-up interview.

Introduction to narrative inquiry

Narrative inquiry is a 'subtype' of qualitative inquiry (Chase 2005). The so-called 'narrative turn', whereby narrative inquiry became an increasingly acceptable methodology in the social sciences started in the 1960s but gathered pace in the 1980s, when the dominant realist/positivist paradigm

was challenged (Riessman 2008). According to Charmaz, 'the narrative turn... renewed attention to research participants' stories and researchers' renditions and interpretations of them' (2002: 302). The 1980s saw further developments in the field, with an increasing focus on the relationship between the researcher and participant, context and narrative form/structure. Mishler was influential in his reformulation of the research interview as a 'speech event': 'a joint product of what interviewees and interviewers talk about together and how they talk with each other' (Mishler, 1986: vii). As Riessman suggests: 'analysing those stories, rather than merely presenting them, was the logical next move' (2008: 17). The researcher's reflexive voice is now an integral part of the narrative. As such, narrative 'position[s] the investigator as part of the field' (Riessman, 2008: 17), a far cry from the positivist, objective social research of the early twentieth century.

Narrative inquiry has many forms including biographical and autobiographical studies, life and oral histories and performance narratives (Chase 2005, Creswell 2007), and is applied across disciplines including anthropology, psychology, linguistics and sociology. For example, there has been a rise in the use of narrative as method of data collection in medical sociological research exploring the illness experience (Elliott 2005). Therefore, in many ways, narrative is an 'umbrella' term for a range of forms and approaches to data collection and analysis (Smith and Sparkes 2008). The approach taken in this study is closest to the oral history, as I focused on a specific period of the life history - long-term cancer survivorship. Oral histories are one of the most common interview formats in narrative inquiry (Clandinin and Connelly 2000).

Narratives and identity (re)construction

Stories tell us about people's lives and the contexts within which they are lived (Phoenix 2008). Those stories are not just personal, but social and cultural, and in this respect they are 'social creations' (Smith and Sparkes,

2008: 18). Events may be unique to the individual but they are 'structured according to socially and culturally shared conventions of telling (Smith and Sparkes, 2008: 18), what Elliott refers to as 'narrative frameworks' (2005: 128), that we have learnt through socialisation. However, whilst we are guided by these cultural frameworks, they do not necessarily determine the content of individual narratives, as these are based on personal experiences and interpretations (Elliott 2005). In this respect, individuals 'actively' engage in a process of identity construction through narrative, all the while aware that this process is situated within wider social contexts (Elliott 2005).

Therefore, narrative is not just a method of data collection but also a process of identity construction (Bury 1982, Charmaz 1983, Mishler 1986, Somers 1994, Mathieson and Stam 1995, Atkinson 1998, Little *et al.* 1998, Charmaz 1999, Bury 2001, Elliott 2005, Smith 2007, Riessman 2008). Linde (1993) argues that life stories 'express our sense of self: who we are and how we got that way' (1993: 3). They help us communicate this sense of self and negotiate it with others (Linde 1993). Stories also have a social function in that they can 'affirm, validate and support our own experiences in relation to those around us. They... shape the individual to the requirements of the society...Stories clarify and maintain our place in the social order of things' (Atkinson, 1998: 10).

Illness narratives

Several commentators have argued that when people experience traumatic events, such as illness, to maintain a sense of continuity of self, and their place in society, they have to reconstruct their identities (Bury 1982, Charmaz 1983, Williams 1984, Charmaz 1987, Carricaburu and Pierret 1995, Mathieson and Stam 1995, Hyden 1997, Skultans 1998). Illness narratives serve 'as a means for understanding the attempts of patients to deal with their life situations and, above all, with the problems of identity that chronic illness

brings with it' (Hyden, 1997: 51). Chronic illness 'usually changes the very foundation of our lives because illness creates new and qualitatively different life conditions... we may be forced to look at the future from a totally different angle. Thus, even the past acquires new meaning: as a part of a lived life' (Hyden, 1997: 52). Skultans (1998) agrees: 'narratives facilitate the search for, and construction of, new meanings in situations where the old meanings no longer work' (1998: 232). For example, if every day routines and relationships are disrupted by illness, these changes may lead to a 'fundamental reconstruction of one's sense of self and identity' (1998: 232). Bury (2001) suggests studying illness narratives sheds light on the disrupted experience of illness, its meanings and actions taken to deal with it - exactly what I attempted to describe in this study.

However, there is a growing body of literature debating the rise of illness narratives as research evidence (Atkinson 1997, Charmaz 1999, Frank 2000, Bury 2001, Charmaz 2002, Atkinson 2010, Frank 2010, Thomas 2010). There is, what Thomas refers to as, a 'rather vitriolic trans-Atlantic journal-based debate' (2010: 647) about narrative research, predominantly between the UK-based Paul Atkinson and US-based Arthur Frank. Atkinson critiques the work of Frank, as well as Mishler and Kleinman. Thomas highlights that the debate is not about the *use* of narrative methods, but 'the claims that can and cannot be made on the basis of narrative data collection, narrative analyses, and the significance of narrative inquiry in the social world' (2010: 648). The debate rests, crudely, on the dichotomy of storyteller vs. story analyst approaches to narrative analysis. Atkinson argues that there is a need to analyse the stories told, whereas the likes of Frank and Kleinman take an ethical stance, suggesting patients' narratives should speak for themselves.

Therefore, at the core of Atkinson's criticisms is what he believes is a lack of methodological rigour in medical sociological research. He argues that authors like Frank and Kleinman privilege the narrator's voice, in their attempts to bear 'witness' and give voice to personal stories of illness. However, he

stresses there needs to be some interpretation of the narrative presented, that it should not be taken at face-value, as it is socially constructed, meaning it has been shaped by the social and cultural contexts within which the narrator lives (including, I would argue, the interview interaction). Atkinson argues that authors 'have made inconsistent and inappropriate claims from narrative approaches' (1997: 326) and that believing in-depth interviews provide a window for truly accessing people's experiences of illness is, in fact, a 'fallacy' (Atkinson 1997). Atkinson does acknowledge the importance of illness narratives but is concerned that the likes of Frank and Kleinman 'have clearly attached particular values to narrative' for advocacy purposes, which he believes are 'illegitimate extrapolations' of narrative (1997: 330). Atkinson feels Frank, Kleinman and Mishler give precedence to the ethical over the methodological (Atkinson 1997) and suggests their ethical concern for maintaining the integrity of the narrator does not 'provide foundations for an adequate methodology' (1997: 334).

My approach to narrative inquiry is similar to that of Thomas (2010) – a mid-way point between Atkinson's objectivity and Frank and Kleinman's ethical, and arguably more subjective, approaches. I agree with Atkinson's points regarding methodological rigour and the need to interpret narratives. However, I also believe that narratives are co-constructed stories, and that the researcher plays a part in that construction. Reflexivity and empathy are therefore necessary not just for the interpretation of those stories, but in order to do the stories justice, to help participants' make sense of their experiences and to use those experiences to help improve the lives of those affected by illness.

Summary of the methodological approach

Table 5.1, adapted from Creswell (2007), demonstrates how complementary case study and narrative approaches are, and justifies the research design I

adopted. Elliott (2005) also outlines key features of narrative, and common interests evident in studies adopting narrative approaches (Figure 5.1). This study was interested in exploring all of them.

Table 5.1: Characteristics of narrative and case study research

Characteristics	Narrative Research	Case Study Research
Focus	Exploring the life of an individual	Developing an in-depth description of a case/cases
Type of problem suited to	Telling stories of individual experiences	Providing an in-depth understanding of a case or cases
Unit of analysis	One or more individuals	Studying an event, program, activity, more than one individual
Data collection forms	Interviews (and documents)	Multiple sources, such as interviews, documents, observation
Data analysis strategies	Analysing data from stories, 'restorying', developing themes	Analysing data through description of the case, as well as cross-case themes
Report	Developing a narrative about the stories of an individual's life	Developing a detailed analysis of one or more cases

(Source: Creswell, 2007: 78-79)

Figure 5.1: Key features of narratives

<p>Key features of narrative</p> <ol style="list-style-type: none"> 1. Temporal or chronological element – representation of a series of events over time 2. Communicates the meaning of events/experiences 3. Important social dimension – narratives are told in a specific social context <p>Common interests in narrative research</p> <ol style="list-style-type: none"> 1. An interest in lived experience 2. A desire to empower participants 3. An interest in process and change over time 4. An interest in representations of self 5. An awareness of the researcher's role in the interview interaction – reflexivity

(Source: Elliott, 2005: 6 & 15)

Stake's belief in the existence of multiple realities sits well with the subtle realist underpinnings of this study. He suggests people have different and conflicting views and understandings of a phenomenon (Stake, 1995) and that '[t]he quintain, contexts, narratives, and understandings are nuanced, internally contradictory, time-bound, and defying easy conceptualisation' (Stake, 2006: 35). However, as a strong constructionist, Stake believes it is impossible to establish the 'best' or most truthful version of reality (Stake 1995) - a view not held by Hammersley. The subtle realist perspective I adopted argues that there are ways to establish the trustworthiness of one claim over another, based on judgements about credibility and plausibility.

Narrative research also presents a specific version of social reality rather than a definitive one, as narratives are time and context dependent. Rorty (1999) suggests we abandon the idea of absolute truth as 'there is no activity called "knowing"... there is simply the process of justifying beliefs to audiences' (1999: 36). Riessman (1993: 15) uses the term 'representation' to demonstrate the 'constructed nature of social science research' and suggests researchers aim for 'believability not certitude' as there are 'narrative truths' - claims about trustworthiness - not absolute truths (1993: 64). These perspectives also fit well with the subtle realist approach I adopted in this study.

Research protocol

Case selection

A relatively small number of cases were selected (n=13), but they have been studied in-depth. Stake argues that the focus is on understanding the individual cases, their uniqueness as well as their commonalities. The cases

are 'a selected group of instances chosen for better understanding of the quintain' (Stake, 2006: 83). As the focus of case study research is on depth of understanding, I take Ritchie *et al.*'s point that 'it is usually better to retain depth of data collection rather than breadth in terms of sample size, even if this means focusing the study on certain parts of the population' (2003a: 104). Stake argues that between four and fifteen cases is the optimum number in multiple-case study research. Any fewer and the 'interactivity' between contexts will not be evident, any more 'provides more uniqueness of interactivity' than researchers and readers can understand (Stake, 2006: 22). Crouch and McKenzie (2006) also argue the case for small sample sizes (less than 20) in exploratory, qualitative research. They suggest that exploring a conceptual framework (e.g. liminality), 'requires small sample sizes so that all emerging material can be kept in the researcher's mind as a totality under investigation at all stages of the research' (2006: 495).

A purposive selection of cases was recruited. Stake's approach argues that 'balance and variety are important; relevance to the quintain and opportunity to learn are usually of greater importance' (Stake, 2006: 26). He suggests selecting cases that we can learn the most from may be 'superior criterion to representativeness' (Stake, 2005: 451). This is because case study research does not aim to generalise to a wider population, so aiming for representativeness is not relevant (Stake 2006). Stake's (2006) three main criteria for selecting cases are:

1. Relevance to the quintain
2. Diversity across contexts
3. Good opportunities to learn about complexity and contexts

According to Stake 'diversity of contexts' (2006: 23) is important, as the point of doing a multiple-case study is to 'examine how the... phenomenon performs in different environments' (2006: 23). Regardless, it is important to explicitly state the rationale for the selection of cases (Creswell, 2007). The

literature review (Chapter 3) identified variables known to impact the experience of cancer survivorship, as well as those about which little is known, or findings are contradictory. As a result, a diverse sample, based on a range of socio-demographic and cancer-related variables was selected.

General inclusion criteria

- Diagnosed with cancer, and completed hospital-based treatment (surgery, chemotherapy and/or radiotherapy) at least five years previously
- Diagnosed in adulthood (18+). Therefore the minimum age was 23
- Disease-free (no recurrence of the primary cancer, second primary or metastatic disease)
- Diagnosed with breast, prostate, colorectal, gynaecological, testicular, bladder cancer or Hodgkin's Lymphoma
- Lived in the South West London boroughs of Hounslow, Richmond, Wandsworth or Kingston²³
- Able to communicate in English

Cancer-related variables of interest

The rationale for only including participants who were disease-free lay in the fact that those living with active disease are likely to have different experiences to those who have been disease-free for at least five years (Miller *et al.* 2008). Focusing on participants who were disease-free allowed me to explore other areas of interest in more depth. Studies have reported contradictory findings regarding the impact of cancer-related variables on the experience of cancer survivorship, and the meaning individuals find in the illness experience (see Chapter 3). I wanted to include individuals who had been diagnosed with breast, prostate, colorectal, gynaecological, testicular,

²³ Note the change to the protocol (Appendix 2 and 3).

bladder cancer or Hodgkin's Lymphoma as they typically have five-year survival rates over 50%²⁴. In England, breast, prostate and colorectal cancer survivors account for over half of all cancer survivors. Incidence of gynaecological, testicular, bladder cancers and Hodgkin's Lymphoma is relatively small but I wanted to ensure the sample comprised common and less common cancers.

Socio-demographic variables of interest

Several studies have explored the relationship between socio-demographic variables and the experience of long-term survivorship, but consistent patterns are yet to emerge (See Chapter 3). Therefore, case selection also considered gender, age, relationship status and parenthood. These variables were selected as data from previous research has produced conflicting findings or posed interesting avenues for further research.

Importance of context

The importance of exploring wider socio-cultural and historical context in my attempts to understand the experience of long-term cancer survivorship is stressed. Life events and other health conditions frame the cancer experience (Blank 2009). Blank suggests 'so much depends on age. Yet so much depends on prior and concurrent experience with illness and other life events' (2009: S427) (See Chapter 3). As such, life events and current health status were explored with participants in the interviews.

²⁴ Five-year survival rates: breast 84%, prostate 81%, bowel c. 50% for men and women, cervical 79%, testicular 97%, Hodgkin's Lymphoma over 80% for men and women, bladder c. 50% for men and women (Office-for-National-Statistics 2011).

Recruitment

Recruitment to the study ran for a year (between June 2010 and June 2011). I planned to focus recruitment on South West London. However, the catchment area was extended to London and the Home Counties, as the number of people who came forward from this area was limited. I considered recruiting participants via GPs. The advantages and disadvantages of this approach are outlined in Table 5.2. However, initial discussions with NHS R&D and staff working at the NCSI, including a GP, were not encouraging with regard to the potential success of this approach. I was told GPs generally do not hold an easily accessible record of when cancer patients finished hospital-based treatment, therefore it would not have been easy for GPs or Practice Managers to generate a list of eligible individuals within their practice from which I could recruit. As a result, I was advised to consider a combination of alternative recruitment strategies.

I drew up a comprehensive list of cancer charities, local cancer support groups and community organisations to approach during the recruitment phase of the study. I approached gatekeepers with a view to attend community/support group meetings to publicise the study. However, in most cases, gatekeepers agreed to publicise the study by putting up a flyer or sharing the information with people they felt it was relevant to (Appendix 5).

Cancer charities and local support groups

Several national cancer charities agreed to post details about the study on their websites, forums or Facebook pages, whilst others publicised the study in their newsletters or through their user involvement initiatives. The majority of participants were recruited via this route. I also approached local cancer support groups and cancer information centres in South West London.

Approaching information centres at hospitals was unsuccessful, but some local cancer support groups shared information with their users and I was able to successfully recruit via this route.

Table 5.2: Advantages and disadvantages of recruitment via GPs

Advantages	Disadvantages
<p>GPs might screen those eligible to take part, based on the study inclusion criteria (thus ensuring participants are ≥ 5 years post-treatment) (Mathers <i>et al.</i> 2009)</p>	<p>Complex NHS ethical procedures</p> <p>Potential cost implications (Ward <i>et al.</i> 2010)</p>
<p>The study is of clinical relevance to GPs as the role of primary care in cancer survivorship will be increasingly important (Department-of-Health 2010)</p>	<p>GPs have more important priorities (caring for patients), therefore research is seen as a luxury they do not have time for (Ward <i>et al.</i> 2010)</p>
<p>Studies adopted by a local Primary Care Research Network (PCRN), are given resources to help with recruitment (Sarre <i>et al.</i> 2008, Ward <i>et al.</i> 2010)</p>	<p>Time consuming in terms of gaining ethical approval and actual recruitment</p>
<p>More likely to access 'silent' groups i.e. those that would not automatically come forward to take part in research such as the elderly, ethnic minority groups, those with low socioeconomic status, etc.</p>	<p>GPs may not inform patients about the study if they do not wish them to take part/think they should not take part (selection bias)</p>

Non-cancer related community/support groups

Other local support organisations approached included Age Concern, the Salvation Army, the Women's Institute, pensioners' forums, community centres, sports clubs, places of worship and libraries/reading groups. I received a mixed response from these sources. Libraries and community centres in some of the boroughs posted the flyer on their notice boards,

subject to space. A couple of local churches also shared the information with relevant members of their congregation. This was not a particularly successful recruitment strategy, however, one participant was recruited because, by chance, she opened the post and saw the flyer.

Snowballing

Snowballing is an approach that involves asking people who have heard about the study, or have already taken part in the study, to recommend others who meet the inclusion criteria. It is a useful approach for recruiting 'dispersed populations' (of which individuals living long-term after a cancer diagnosis could be considered) (Ritchie *et al.* 2003a). However, one disadvantage is that participants recruited this way are likely to know each other, which may have implications for confidentiality and anonymity. The diversity of the sample may also be compromised. However, this can be mitigated by asking participants to avoid recommending family/friends (Ritchie *et al.* 2003a).

Recruitment process

Potential participants generally contacted me directly via email as a result of seeing the flyer, or hearing about the study from a gatekeeper. I telephoned them to introduce myself, and outlined the purpose of the study and what was involved, as well as running through a screening crib sheet to assess whether they met the inclusion criteria. If they did, I sent out an information sheet and consent form. Once I receive their signed consent form, I arranged the first interview. (See Appendix 4 for the recruitment flow diagram; information sheet and consent form).

'Significant others' were recruited via the participants who had been diagnosed with cancer. Participants were informed during the initial screening call, and in the information sheet, of the study's aim to also interview people close to those living long-term after a cancer diagnosis. It was envisaged that

at the first interview, participants would be given a nomination form to fill in, having already discussed the study with their 'significant other'. In the event, the nomination form was not used as participants had normally discussed the study with their 'significant other' prior to the first interview and already given me the 'significant other's' contact details. I then contacted the 'significant other' separately to discuss the study, and whether they would be willing to take part. Recruitment then proceeded as for the participants who had been diagnosed with cancer.

In reality, recruitment was slower than anticipated so, whilst I had planned to purposively sample participants based on a range of socio-demographic and cancer-specific criteria, if people coming forward met the inclusion criteria, they were invited to interview. However, as recruitment progressed it was necessary to prioritise the selection criteria to ensure 'diversity of contexts' was achieved (Ritchie *et al.* 2003a, Stake 2006). Therefore, case selection was, in part, pragmatic (Silverman 2010). For example, I wanted to include male and female participants who had been diagnosed with colorectal cancer, in order to explore the impact of the disease by gender, but after nine months of recruitment, no one had come forward. I decided to put a hold on recruitment for certain groups (in particular women with breast cancer) and specifically target bowel cancer charities. As a result of this strategy, I successfully recruited both male and female participants who had been diagnosed with colorectal (bowel) cancer.

Limitations to the recruitment strategy are presented in Chapter 10, as part of my commentary on the quality of the research conducted.

Ethical considerations

Ethical approval was granted by the University of Nottingham Medical School Ethics Committee in June 2010 (See Appendices 1 and 3).

Impact on participants

I was concerned about the impact of the study on participants as the interviews were likely to explore emotive and sometimes distressing experiences. I believed that for the majority, telling their story would be of benefit to them, but equally could not be sure participants were not distressed by the experience (Johnson and Macleod Clarke 2003). As Johnson and Macleod Clarke state, whilst 'participants value the opportunity to reflect on their experiences, it is nevertheless not difficult to imagine that reflecting in the face of emotional pain is likely to be a distressing experience' (2003: 430). It was therefore important to conduct the interviews in a professional, yet sensitive, manner making it clear to participants that they could stop the interview at any time and, if necessary, withdraw from the study. It was also important to have strategies in place to end the interview appropriately. For example, if a participant became upset, I would have referred them to an organisation such as Macmillan Cancer Support. I took details of Macmillan's helpline and website to the interviews. In the event, sharing these details was not necessary. Debriefing at the end of the interviews was also important. I talked about the practicalities of the study, for example, when the report would be available, and then steered the conversation towards something unrelated to cancer, such as what they were doing afterwards, to hopefully get the participant thinking about something other than cancer.

Impact on the researcher

I was also aware of the emotional impact interviewing people affected by cancer might have on me. Johnson and Macleod Clarke (2003) conducted a study exploring the impact on researchers carrying out research in sensitive areas, including cancer. Researchers experienced a number of difficulties, some of which I can identify with. These included the unpredictability of research in this area, the extent to which "emotional and moral unease" can be generated for the researcher (2003: 423) (including concerns about

confidentiality, the impact of the interview on the participant, etc.), and implications for the researcher (contact anxiety, facing their own fears about the research topic, etc.) (Johnson and Macleod Clarke 2003). I maintained a reflexive journal and held post-interview debriefing sessions to discuss the interview process and any concerns I had. This was with my supervisors, colleagues who conduct research in the same field, or my family. This not only served as a useful analytical tool, but also helped me look after myself during the study.

Anonymity and confidentiality

Any information collected about participants during the course of the research is kept on a password-protected computer and remained strictly confidential. The interviews were digitally recorded. These recordings are also held on a password-protected computer and only accessed by myself, and occasionally my supervisors. All data are held in accordance with the Data Protection Act. A participant ID was assigned to all individuals who contacted me about the study. This was noted on the screening form alongside their name and contact details. The screening form was kept securely and separately from interview transcripts and the analysis. Interview transcripts, analysis, findings and quotes only referred to the participant ID or a pseudonym.

As researchers we have to make moral choices about what we 'ask, record or present' in the process of our research (Anspach and Mizrachi 2006). For example, we make decisions about what to reveal or conceal in the interests of confidentiality. Kaiser (2009) states that 'qualitative researchers face a conflict between conveying detailed, accurate accounts of the social world and protecting the identities of the individuals who participated in the research' (2009: 1632). She critically outlined what she referred to as the 'dominant approach' to maintaining confidentiality, which focuses on making participants unidentifiable, with an alternative that 'emphasises a more

nuanced consent process and takes into account the audiences of one's research' (2009: 1634).

In the dominant approach, the researcher takes responsibility for deciding what aspects of participants' stories need to be changed to maintain confidentiality. Kaiser outlines how issues of confidentiality can be addressed through 'data cleaning', for example, removing names, addresses, etc. However, 'unique combinations of traits can be used to identify respondents' (2009: 1635). Although data cleaning may remove 'personal identifiers', 'contextual identifiers' in participants' stories will remain' (2009: 1635), for example, unusual life events. In these cases, details within the data may also need to be altered. Yet, doing so can 'alter or destroy the original meaning of the data' (2009: 1635). Readers will typically not know the extent to which data cleaning has taken place and are 'therefore unable to consider the significance of the changes for their interpretations of the data or for the validity of the data' (2009: 1635). The alternative to changing key details, is to leave some data out all together. The issue here is that data might provide key insights that could inform policy or practice if disseminated (Kaiser 2009). A key weakness to the dominant approach is that whilst it may ensure 'external confidentiality' i.e. to the outside world, it does not necessarily ensure confidentiality if findings are read by those close to the participant (Kaiser 2009).

Kaiser's alternative approach seeks to ensure participants are better informed about the use of their data – who the audience for the research will be and how it will be disseminated – and revising the informed consent process. She feels consent should be an ongoing process, which presents participants with a range of confidentiality options. Kaiser said participants may then opt to be identified, but need to be made aware that 'the final presentation of their views might not be entirely what they envisioned' (2009: 1638).

I adopted the 'dominant approach'. Names, addresses, hospitals, consultants, job titles, etc. were anonymised in a 'data cleaning' exercise. In addition, specific details about the participants and their 'significant others' were sometimes altered. For example, if a participant mentioned they had a 'son', I might have reported that they had a 'child'. Here, whilst the specifics may have been altered, every effort was made to ensure the context or meaning of the data was not compromised. I also chose to leave some data out of the study. It was clear in some cases that 'contextual identifiers' could threaten the confidentiality of participants (Kaiser 2009). Kaiser said 'shelving the data about a painful part of someone's cancer experience was unsettling' (2009: 1634). I too feel uncomfortable not presenting exactly what was shared by the participants, but at the same time, the in-depth, context-rich approach I took means someone could read a case and identify a participant. I am ethically and morally obligated to prevent that from happening.

Informed consent

All potential participants received an information sheet and consent form. They had the opportunity to discuss the study with me prior to, and after, receiving the information sheet. If they decided to take part, they signed a consent form and sent it back to me before any interviews took place. I made participants aware through the information sheet and discussions prior to the interviews that they were able to withdraw at any time without giving an explanation.

Health and safety issues for lone researchers

Health and safety issues regarding lone researchers were taken into consideration. I consulted the School of Nursing Guidance for staff who undertake research as lone workers, as well as the Suzy Lamplugh Trust and my supervisors. I subsequently conducted a risk assessment and followed examples of best practice outlined in the Guidance, to ensure risks associated

with interviewing members of the public alone were minimised. I ensured a colleague or friend knew who I was meeting, where and at what time. I always carried a mobile phone with me and gave a time by which I would call to let that person know I was safe.

Many researchers conducting research on cancer survivorship conduct interviews in participants' homes. The risk assessment, alongside discussions with my supervisors, deemed this generally unsuitable, as participants were members of the public and, as such, had not been vetted, for example, by healthcare professionals. Therefore the majority of interviews took place in private rooms in local community settings, where other members of the public/staff would be available if necessary. If this was not possible, the individual case was raised with my supervisors and a decision made as to where/how the interview could take place. Alternatives included conducting interviews by telephone. However, in the event, some interviews were conducted in participants' homes. In these exceptional circumstances, participants were accounted for by the gatekeeper through whom they were recruited, for example, a cancer volunteer coordinator.

Interview process

I planned to conduct up to three interviews for each case: two with the individual who was living five years or more after a cancer diagnosis and one separate interview with a 'significant other'. Multiple interviews aimed to give depth to each case. The approach I took allowed the individual who had been diagnosed with cancer to tell their story in the own way, but also gave me the opportunity to explore my specific research interest in long-term cancer survivorship. It was felt interviews with 'significant others' were necessary to explore the impact of cancer on relationships, as well as elements of Little *et al.*'s (1998) concept of liminality. For example, to explore 'communicative alienation' it was important to understand how 'significant others' perceived

the individual diagnosed with cancer, and the impact they feel cancer has had on their relationship with them²⁵.

A single, open-ended question was asked, aimed at 'inducing narrative' (Wengraf, 2001: 113). Wengraf (2001) refers to 'single questions induce narrative' (SQUIN). A full SQUIN would be the life story approach, but there can also be SQUIN that have a 'conceptual focus', for example, a specific phase in someone's life or focus on specific issues like an illness, a relationship, a personal experience, etc. as per my study (Wengraf 2001). Wengraf asserts that, in his biographic-narrative interpretive method (BNIM), the researcher engages in little further intervention after the SQUIN, thus giving control to the participant to allow them to tell their story in their own way. Encouraging, rather than directing, narrative is the primary purpose of the interview interaction (Holstein and Gubrium 1995).

In some ways, my approach was similar to Wengraf's BNIM (Figure 5.2). I did not explicitly follow his method, just some of his ideas. The BNIM includes at least two interviews, which cover three 'sub-sessions'. He suggests session two should occur quite soon after session one (often after a short break), and that session three requires analysis of first two sessions (Wengraf 2001). My approach combined sessions one and two in the first interview, and then I used an approach similar to session three in the follow-up interview. Essentially, I allowed the participant to share their story in their own way, and then probed that story for further detail. A semi-structured interview schedule was used in the follow-up interview, which covered questions pertaining to my research objectives (Appendix 13). I also used the follow-up interview to check dates, treatments, etc. and clarify anything I was unsure of from the narrative interview. However, as Figure 5.3 shows, the interview process evolved to reach this point. It did not always proceed as planned, as a result of challenges faced by myself as an interviewer (See Challenge 1 below

²⁵ It was beyond the scope of the study to explore the impact of cancer on the 'significant other'.

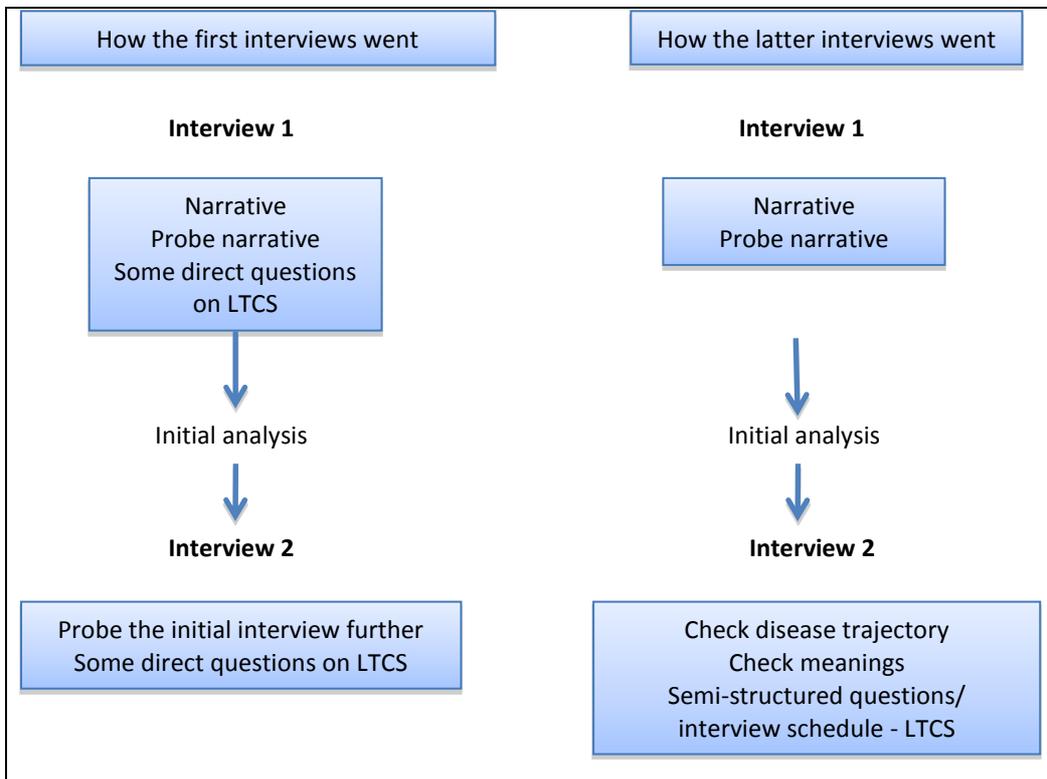
and Figure 5.4) and by participants. For example, some participants found it difficult to sustain their narrative. In these instances, I asked broad questions from the follow-up interview schedule to help them share their story in more depth. Flexibility in the approach was key to successful interviews.

Figure 5.2: The biographic-narrative interpretive method (BNIM)

Sub-session 1	Initial elaboration of the story around topics Single initial question Note down topics that come up in the narrative
Sub-session 2	Extracting more story from the topics discussed in sub-session 1 Asked for more information about the topics raised Follow the order the topics were raised in, use the language they used No additional topics to be raised by the interviewer
Sub-session 3	Questions arising from the analysis Develop a set of questions in light of central research questions Directed by the interviewer, structured Can mention topics not mentioned previously

(Wengraf, 2001: 120).

Figure 5.3: Evolution of the interview process



Challenge 1: 'Going with the flow'

Gunaratnam suggests one of the most challenging skills for a narrative researcher is to “go with the flow” (2009: 50) - to allow the narrative to emerge in its own way, without interruption, ‘no matter how incoherent or “off the point”’ accounts can feel (2009: 50). This is because seemingly unrelated parts of the narrative can be connected and it is only by allowing the shape or “gestalt” of the story to develop that the meaning of these seemingly unrelated narratives can be explicated (Gunaratnam 2009). To do this, Gunaratnam advocates Wengraf’s approach: asking a SQUIN, with subsequent questions drawn directly from the narrative. I tried to adopt this approach in the narrative interviews. However, Figure 5.4 is an excerpt from my reflexive log, which outlines how difficult I found it to ‘go with the flow’.

Figure 5.4: My experience of ‘going with the flow’

I found it very difficult to allow the narrative to emerge in its own way, without interruption. Initially I felt I wasn’t actually doing anything, that I had to ask probing questions, but as soon as I asked one question, participants looked to me for further questions, and instantly the free-flowing narrative, shaped by the participant, was over. So I had to jot down what I wanted to find out more about (which I felt self-conscious doing as I worried participants might be concerned about what I was noting down) and forced myself to wait until they had finished their story. This felt really disjointed to begin with, going back to probe something they had said half an hour before, but it did allow the narrative to flow and let the participant tell their story on their terms. It got easier, but it was by no means natural to me.

Challenge 2: Separate or joint interviews with individuals diagnosed with cancer and their ‘significant others’?

An issue discussed at length with my supervisors was whether interviews with individuals who had been diagnosed and their ‘significant others’ should be conducted separately or jointly. There are merits and limitations to each approach, as well as ethical considerations (Table 5.3, based on Taylor and de Vocht (2011)). Taylor and de Vocht suggest the presence of a partner can

'facilitate or constrain the narrative within an interview, and can therefore either enhance or limit the richness of the data collected' (2011: 1585). During a study on the needs of cancer patients and carers, the researcher found that joint interviews generated rich data and highlighted avenues for further inquiry (Morris 2001). Morris felt a partner's presence 'did not seem to inhibit talk about sensitive subjects, such as death and difficult emotions; it even at times provoked extra disclosure' (2001: 565). However, joint interviews can be a source of conflict or distress if the relationship is under strain, perhaps as a result of the topic under study (Taylor and de Vocht 2011).

Table 5.3: Advantages and disadvantages of separate and joint interviews

Type	Advantages	Disadvantages
Joint	<p>Can corroborate or supplement each other's stories, and 'probe, correct, challenge, or introduce fresh themes' for discussion</p> <p>Provides insights into the dynamics of the couple</p>	<p>Potential to cause distress</p> <p>Responses to sensitive questions influenced by presence of a spouse. Feel they need to give 'socially acceptable' answers to both researcher and spouse</p> <p>Might expose conflict within the relationship</p> <p>Potential for harm if one partner discloses something the other was unaware of</p>
Separate	<p>Able to express own views: 'people's experiences are not identical to those of their partners, and capturing these unique perspectives might be easier in separate interviews'</p> <p>Can speak without inhibition</p> <p>Therapeutic effect</p>	<p>Potential to cause distress</p> <p>There is a possibility that participants will be able to recognise their partners in reports/findings so care needs to be taken to preserve anonymity</p>

(Taylor and de Vocht, 2011: 1577)

Forbat and Henderson (2003) discussed some of the ethical issues that arise when conducting separate interviews with two people within a relationship. For example, if one of the participants mentions a particular episode, they question whether it would be ethical to ask the other participant directly about that episode. If the other participant does speak about it, it raises questions about the ethics of publishing accounts from both participants alongside each other and confidentiality between the participants (Forbat and Henderson 2003). For them, the challenge of confidentiality arises because the amount of information that could identify participants is doubled. They suggest 'careful and critical fictionalising of accounts that are used in public/academic domains' is needed to anonymise participant stories (2003: 1459).

I decided to conduct the interviews separately (See Appendices 13 and 14 for the interview schedules). The rationale for this was based, in part, on my professional background. I am a social scientist, not a nurse, or relationship counsellor. I did not feel equipped to manage any potential difficulties that may have arisen during the conduct of joint interviews. Also, I wanted participants and their 'significant others' to be able to speak without inhibition, and felt they would be more able to do so in one-to-one interviews. It was made clear in the information sheets to both participants and 'significant others' that they were to be interviewed separately. However, I was aware that some individuals might not feel comfortable with this. The situation arose on one occasion so I went ahead with a joint interview. The participants jogged each other's memories, clarified, elaborated and challenged. However, I did feel uncomfortable when issues arose regarding their relationship. I did not want, nor did I feel able, to discuss the problems in their relationship. Equally, I did not want to leave them to deal with those feelings when the interview was over.

Transcription

Interviews were recorded and transcribed soon afterwards. Transcribing is an interpretive act. How interviews are transcribed depends on whether the analysis focuses on the content or structure of the narrative. All interviews were transcribed verbatim but umms, pauses, overlapping speech, etc. were omitted, as the focus was generally on the content of the narratives. I transcribed just over half of the interviews, and the remainder were sent to a specialist transcription service, recommended by the University. Whilst I wanted to gain transcribing experience and start to immerse myself in the data, time constraints²⁶ meant it was necessary to send some recordings to a transcriber. I transcribed particularly emotive or sensitive interviews as I did not want the transcriber to become distressed. Equally, if I was concerned a participant might be identified, I transcribed the interview to maintain confidentiality.

Analytical approach

Riessman argues that narrative research has 'realist, postmodern and constructionist strands' (2008: 13) which means that researchers adopting these different perspectives argue over the most appropriate approach to analysis. However, what is clear is that narratives are interpretive and, in turn, require interpretation (Riessman 1993).

Finding a balance between the 'whats' and 'hows' of knowledge production

The narrative turn saw an increasing focus on the relationship between the researcher and participant. The narrative interview is as an active process between the interviewer and the interviewee (Mishler 1986, Holstein and

²⁶ I planned to conduct the follow-up interview 3 to 4 weeks after the first narrative interview.

Gubrium 1995, Holstein and Gubrium 2004). In taking this 'active', co-constructed approach to the interview interaction, Holstein and Gubrium highlight that paying attention to 'both the interview process and the products that interviews generate' (2004: 142) is important. As such, a 'dual interest in the *hows* and *whats* of meaning production goes hand in hand' (Holstein and Gubrium, 2004: 142). Whilst they adopt a constructionist epistemology, Holstein and Gubrium acknowledge a balance is needed between the realist focus on the 'whats' (descriptions of experience) as well as the constructionist perspective on *how* interview talk is produced: 'the focus is as much on the assembly process as on what is assembled' (2004: 156). In this respect they do not allow the data to 'speak for themselves' (2004: 156) but the process by which knowledge is actively, and jointly, constructed by the participant and interviewer, is considered. Whilst Holstein and Gubrium argue that understanding the 'hows of social process' is critical to understanding the 'whats of lived experience' (1995: 5), too much focus on the 'hows' neglects the significance of the 'whats'. As such, Holstein and Gubrium suggest that a balance is needed, with a greater focus on 'substance and content' (1995: 5). Whilst realists are primarily interested in the content of interviews, reflexive discussion of the interview interaction (what Mishler (1986) referred to as the 'interactional context') 'demonstrates that they [are] also sensitive to the way that meaning [is] constructed as part of the interview interaction' (Elliott, 2005: 20).

This approach fits well with the subtle realist underpinnings of the study, and formed the basis of my analytical approach. Content (the 'whats') was of primary importance, but reflexive discussion of the interview interaction addressed my role in the construction of knowledge (the 'how'). I was also interested in the discourse of 'survivorship', so attention was paid to language in terms of how participants described themselves, and their perceptions of terminology used to describe them. To explore the interview interaction I engaged in various reflexive practices. I maintained both reflexive and methods logs (Carter 1993, Shapiro *et al.* 1997, Clandinin and Connelly 2000)

and held post-interview debriefs to discuss any concerns/learnings taken from the interviews. Interviewees were also asked about the interview experience, including what motivated them to take part.

Approaches to narrative analysis

Lieblich *et al.* (1998) developed a model for organising types of narrative analysis: holistic vs. categorical and content vs. form approaches. Categorical approaches focus on content analysis: ‘the original story is dissected, and sections or single words belonging to a defined category are collected from the entire story or from several texts belonging to a number of narrators’ (1998: 12). Holistic approaches focus on the life story as a whole where ‘sections of the text are interpreted in the context of other parts of the narrative’ (1998: 12). These two dimensions intersect to form a matrix (Figure 5.5). However, Lieblich *et al.* (1998) acknowledge the categories are not clear-cut and as such there are possibilities for ‘middle points’ within the matrix. Indeed, they suggest many studies combine various dimensions and that their dichotomies should really be viewed as two ‘continua’. For example, they argue that even when considering form, content cannot be ignored, neither can separating the category from the whole.

Figure 5.5: Lieblich *et al.*'s matrix of approaches to narrative analysis

Holistic-content (case studies)	Holistic-form (plots e.g. comedy, tragedy)
Categorical-content (content analysis)	Categorical-form (‘discrete stylistic or linguistic characteristics of defined units of the narrative’ (1998: 13))

(Source: Lieblich *et al.*, 1998)

Holistic-content approach: The three-dimensional narrative inquiry space

This study adopted a holistic-content approach to analysing the narratives. This approach is appropriate when analysis aims to understanding the meaning of an individual's story (Ollerenshaw and Creswell 2002). The specific holistic-content approach underpinning this study was Clandinin and Connelly's (2000) three-dimensional narrative inquiry space.

Clandinin and Connelly cite John Dewey's writings on the nature of experience as their 'conceptual, imaginative backdrop' (2000: 2) to the development of the three-dimensional narrative inquiry space. Dewey believed experience to be both personal and social. Clandinin and Connelly explicate this assertion: 'people are individuals and need to be understood as such, but they cannot be understood only as individuals. They are always in relation, always in a social context' (2000: 2). Another of Dewey's elements of experience is continuity: 'experiences grow out of other experiences, and experiences lead to further experiences... each point has a past experiential base and leads to an experiential future' (Clandinin and Connelly, 2000: 2). Bringing these two elements (personal and social, and continuity) together, Clandinin and Connelly argue that we 'move back and forth between the personal and the social, simultaneously thinking about the past, present, and future, and do so in ever-expanding social milieus' (2000: 2-3). Added to the *personal-social* and *continuity* is *place* as the third dimension 'which attends to the specific concrete physical and topological boundaries of inquiry landscapes' (2000: 51). Ollerenshaw and Creswell (2002) outline how a researcher can analyse these aspects of the narrative inquiry space (Figure 5.6), as well as features of the narrative inquiry space (Figure 5.7).

Figure 5.6: Aspects of the three-dimensional narrative inquiry space

Interaction involves both the personal and social. The researcher analyses a transcript for the personal experiences of the storyteller as well as the interaction of the individual with other people. Other people may have different intentions, purposes, and points of view on the topic of the story.

Continuity (temporality) is central to narrative research. The researcher analyses a transcript for information about the storyteller's past experiences. In addition, it is analysed for present experiences, or action to occur in the future. This way, the analyst considers the past, present, and future.

Situation (place) involves the researcher looking for specific situations in the storyteller's landscape. This involves the physical places or the sequence of the storyteller's places.

(Ollerenshaw and Creswell, 2002: 339)

Figure 5.7: Features of three-dimensional narrative inquiry space

- Experience-orientated
- Holistic
- Personal and social
- Many alternative logics to sequencing
- Describing experiences
- Co-researchers with participants, negotiate relationships, purposes, transitions

(Ollerenshaw and Creswell, 2002: 344)

Individual case analysis

Objective: Develop detailed case study write-ups for each individual diagnosed with cancer, describing their experiences of long-term cancer survivorship.

Analysis of individual narratives took a 'restorying' approach (Creswell 2007). Stories and events are rarely told in chronological order. Therefore, 'restorying' is gathering a story, analysing it for key elements including "turning points", and then rewriting it into a chronological sequence. Key

themes are then identified and rich detail about context provided. This leads to a description of the story and themes that emerge from it (Ollerenshaw and Creswell 2002, Creswell 2007). An awareness of working within the three-dimensional narrative inquiry space was maintained throughout the 'restorying'.

To facilitate the analysis of individual cases, and writing up the 'restoried' accounts, I adopted Hall's (2011) summary narrative assessment (SNA) approach, where a template is designed to identify the most relevant data from each account. The template is based on the aims of the study, genres of story and central themes of interest in the research (Hall 2011). Therefore, my template focused on the broad themes of participants' daily lives and the life course; searching for meaning; self and relationships; and the concept of 'survivorship' (Appendix 15). Quotes are used throughout the account to illustrate the summarised stories. Hall also conducts subanalyses including plotting life trajectories. I plotted cancer trajectories for each participant, highlighting key moments/turning points in their cancer story, as well as in their wider life story, which proved a useful way of representing, and interpreting, the data.

The SNA is a contextual form of analysis, which does not use the same 'lens across the whole [dataset]' (Mason, 2002: 165). Looking at individual cases or contexts and saying something about those parts specifically, 'it is a practice guided by a search both for the *particular in context* rather than the common or consistent, and the *holistic* rather than the cross-sectional' (2002: 165). This approach is often used in narrative and case study research. By taking this approach, I was able to analyse 'the holistic "unit", or case study, to try to produce an explanation of processes, practices... that characterise that unit' (2002: 168). As such, subthemes, genres, etc. might differ from case to case. In my study, top-level themes were often similar, as participants knew I was interested in identity, relationships, etc. but whilst some may have discussed the impact of body image and sexuality on their sense of self, for example,

others did not. The template gave me both structure and flexibility, allowing me to identify key themes and subthemes from within a specific case. The SNA and subanalyses then formed the basis of the cross-case analysis.

Analysis of 'significant other' data

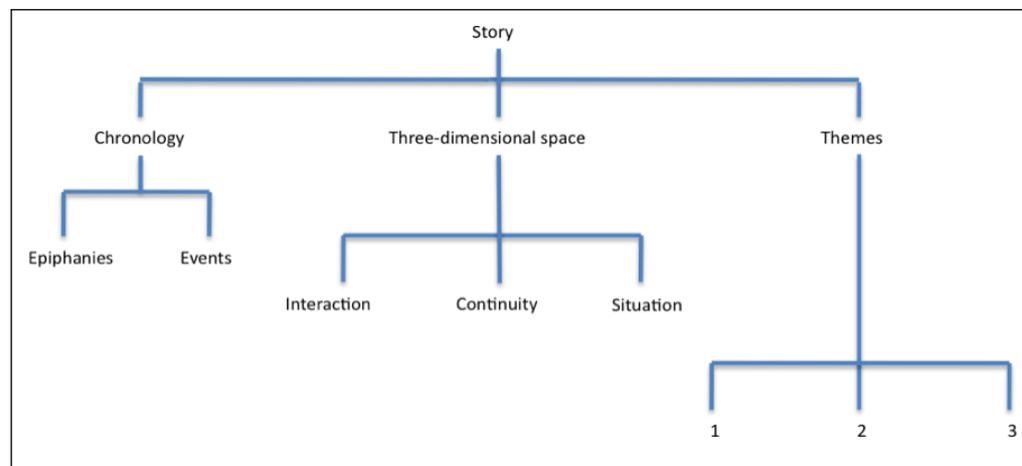
Conducting the interviews separately had implications for how I analysed and presented the data collected on the individuals who had been diagnosed with cancer and their 'significant others'. As for the interviews themselves, it was a question of whether to present the data separately or together. Eisikovits and Koren (2010) suggest dyadic analysis deepens the findings by identifying overlap and contrast between the individual accounts which captures the individual's subjective experiences, as well as events/feelings experienced as a couple. I planned to conduct separate interviews with each participant, which is Eisikovits and Koren's (2010) preferred method because it 'enables each protagonist to tell the story from his or her own perspective, without having to consider the reaction of the other when voicing criticism or bringing up sensitive topics' (2010: 1644). I wanted to conduct separate interviews but analyse the stories dyadically, exploring consensus and contradiction in the accounts presented by the individuals who were diagnosed with cancer and their 'significant other'. However, this posed ethical problems. Fundamentally, I felt it would be difficult to maintain confidentiality when information shared in the interviews supported or contradicted what another had said.

As a result, I decided to conduct a separate thematic analysis of the 'significant other' data. This meant I would not be able to develop embedded case studies as originally proposed, as the data from those diagnosed with cancer and their 'significant others' would not be analysed and presented together. Transcribed interviews were coded manually according to key concepts evident in the data. I then used A3 mind maps to chart these key concepts and collapse them into broad themes across the 'significant other' accounts. These broad themes are presented in Chapter 8.

Summary of individual case analysis

- Descriptive accounts
- ‘Restorying’ individual experiences of long-term cancer survivorship
- Detailed case study write-ups
- Stake’s (1995, 2006) ‘direct interpretation’
- *Within*-case analysis

Figure 5.8: Template for analysing narrative interviews



(Source: adapted from Creswell, 2007)

Multiple-case analysis

Objective: Describe the experience of long-term cancer survivorship at the aggregate level.

As outlined above, narrative analysis initially provided a detailed description of individual cases - what Stake refers to as ‘direct interpretation’ (Stake 1995). This was followed by ‘categorical aggregation’ of instances across cases until something could be said about the quintain (long-term cancer survivorship) as a whole (Stake 1995). Stake argues that one of the most important tasks in multiple-case research is to show how the phenomenon differs in different contexts (Stake 2006). For me, understanding the quintain was of primary importance, so the purpose of my research was to apply

findings from individual cases to the research questions pertaining to the quintain. This had to be achieved whilst keeping in mind the 'contextual meaning' of each case.

Stake suggests that interpretation and understanding involves searching for patterns in the data. He refers to this a 'correspondence' and argues that important meanings will come from the reappearance of instances within and across cases (1995: 78). Repetition of instances across cases gives some indication of 'interactivity' of cases across contexts (Stake 2006).

Stake (2006) offers three 'tracks' for cross-case analysis:

1. 'Emphasising case findings' – this is Stake's preferred option as it maintains the case findings and context. He regards it as the most difficult analytical option but it is the pertinent track when individual findings are more important than the quintain.
2. 'Merging case findings' – similar findings are merged, but some context is maintained. This option is useful where understanding the quintain is more important than the individual cases, but where some degree of contextual understanding is still desired.
3. 'Providing factors for analysis' - a much more quantitative method. Context is lost in this approach.

Track 2 was the most appropriate option for this study. In order to merge the case findings, several methods were adopted. Instead of comparing the features of each case as though they were like for like, I chose to 'compare the *explanation* of the first case with the explanation of the second, both explanations having been derived from a holistic rather than cross-sectional analysis' (Mason, 2002: 168). Essentially, I took my interpretation of each case, and compared those interpretations across cases, rather than conducting, for example, a cross-sectional thematic analysis across cases. I pulled out key elements from each 'restored' account and collapsed these

into broad themes across cases. To do so, I again developed A3 mind maps to map key themes from the individual case studies. I also used my research memos - notes and thoughts written during the individual case analysis – and thoughts jotted down in my methods and reflexive logs. I had written ‘CROSS’ in the margins of the research memos to identify commonalities and differences across participants’ accounts. I then compiled an Excel spreadsheet to collate the data.

Building typologies (classifications according to a general type) was another important element of the cross-case analysis (Bryman and Burgess 1994) as it enabled me to ‘delineate subgroups within a general category’ (1994: 7). Hall (2011) also advocates identifying the ‘narrative motif’ or ‘core’ that underpins all cases. Drawing on the broad categories identified through the process of collapsing key elements from each ‘restoried’ account, I explored whether it was possible to identify a core theme that underpinned all cases.

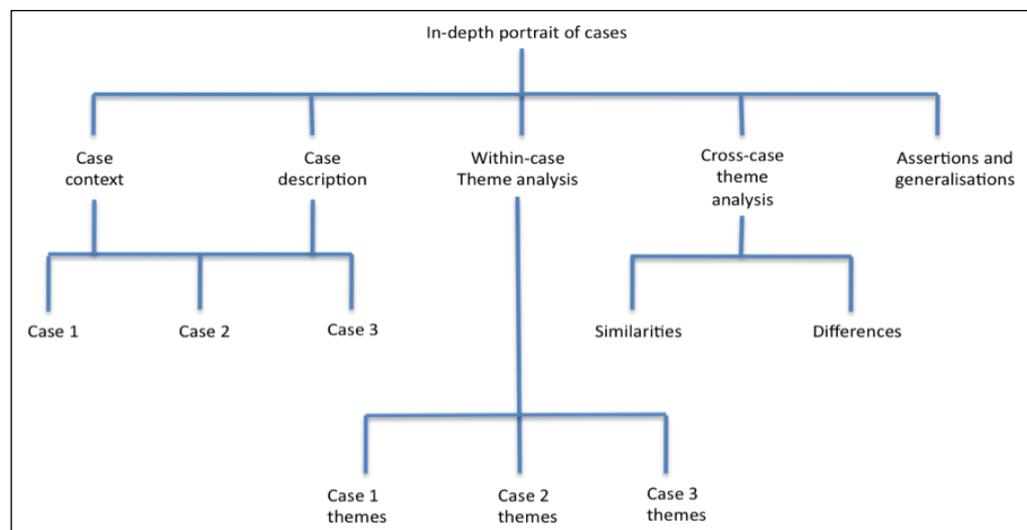
To compare and contrast the accounts of those diagnosed with cancer and ‘significant others’ I conducted a form of dyadic analysis, drawing on the work of Eisikovits and Koren (2010). Rather than analyse the specific pairs of individuals diagnosed and their ‘significant others’, I explored similarities and differences between accounts at the aggregate level. To do so, I interrogated the broad themes identified in the cross-case analysis of the restoried accounts as well as themes identified in the thematic analysis of ‘significant other’ data. The analysis highlighted instances where accounts shared by those diagnosed and their loved ones differed and explored what the implications of these contrasting accounts of the cancer experience might be.

Summary of multiple case analysis

- Describe the experience of long-term survivorship as a whole
- ‘Categorical aggregation’ (Stake 1995, Stake 2006)
- Explore similarities and differences across cases

- ‘Merge’ case findings to develop higher-order categories/themes and explore relationships between categories to say something about the experience of long-term cancer survivorship as a whole (for example, typologies, identifying a core theme that underpins cases)
- Explore how long-term cancer survivorship differs in different contexts
- Explore similarities and differences between the accounts of those diagnosed with cancer and ‘significant others’

Figure 5.9: Template for analysing a multiple case study



(Source: Creswell, 2007)

Beyond description: Exploring the applicability of liminality

Objective: Explore the applicability of Little *et al.*'s (1998) ‘sustained’ liminality, and elements of ‘cancer patientness’, ‘communicative alienation’ and ‘boundedness’ for understanding experiences of long-term survivorship.

Bryman argues that ‘there is a growing view that qualitative research ought to be more consciously driven by theoretical concerns’ (1988: 91). Indeed, with respect to case study research, he believes ‘case study data become important when the researcher seeks to integrate them with a theoretical context’ (1988: 90-91). In this respect, case study research should aim to

generalise cases to a theory rather than a population (Bryman 1988). He concludes that 'theoretical reasoning [is] the crux of the issue of case study generalisation' (Bryman, 1988: 92). This leads those conducting case study research to enter into the wider qualitative research debate regarding the place of theory in the discipline (Bryman 1988).

The concern is that being guided by theory early on in a study may 'prejudice the researcher's ability to see through the eyes of his or her subjects... and blind them... to the unusual and unanticipated facets of a strand of social reality. Moreover, these unanticipated facets of social life may be important to the participants' (Bryman, 1988: 86-87). In this study, I sought to describe experiences of long-term survivorship first. I then went on to explore the utility of liminality. I was therefore open to the fact that other theories could prove more useful in understanding the experience of long-term cancer survivorship, or that liminality could be experienced in a different way to that already reported. Having said this, I do acknowledge that it would have been impossible for me to completely set aside my knowledge of liminality whilst 'restorying' the individual cases and conducting the cross-case analysis. Indeed, my research memos demonstrate instances where I noted a particular experience/action/emotion resonated with the concept of liminality. I think this is inevitable, and unavoidable, as we all come to research with a priori thoughts, feelings and experiences. These need to be acknowledged throughout reflexive research practice, which is why I maintained methods and reflexive logs, and research memos, and have made reference to these throughout the research process.

Following an approach taken by Sekse *et al.* (2009) I decided to present the within- and cross-case analyses in a series of findings chapters (Chapters 7, 8 and 9) and then discussed those findings in relation to the theory of liminality in a separate Discussion chapter (Chapter 10).

When exploring the utility of liminality, I considered the following questions:

- Do participants experience 'sustained' liminality? If yes, what does this mean to them day-to-day?
- Do participants experience Little *et al.*'s (1998) elements of liminality? If yes, how do these elements manifest themselves day to day, and what do they mean for individuals and those close to them?

I looked for evidence of Little *et al.*'s (1998) 'sustained' liminality and elements of 'cancer patientness', 'communicative alienation' and 'boundedness' in the 'restored' accounts and cross-case analyses. I highlighted exemplar cases²⁷, for example, cases demonstrating evidence of liminality, and those that did not. I also considered other applications, and conceptualisations, of liminality, already discussed in Chapter 4, to ensure I was not trying to fit my data to Little *et al.*'s (1998) conceptualisation.

Objective: Draw assertions about long-term survivorship and liminality. If some participants live in a state of 'sustained' liminality, but others do not, explore *why* might this be?

According to Ritchie *et al.* (2003) a good starting point when attempting to detect associations between experiences and factors underpinning them is existing research/theory, as are reflections during fieldwork and analysis. Explanations require a leap, leaving the cases behind to some extent and interpreting what has been said. However, the explanations still need to be supported by data from cases (Ritchie *et al.* 2003b).

Approaches used to find explanations included further *within* and *cross* case analysis, developing a central chart to map key themes and variables of interest and using the typology and exemplar cases. It was important to

²⁷ In a study by Grinyer (2010), purposive sampling was used to select exemplar cases that illustrated issues raised by the wider sub-set of participants. Diverse cases highlighted the range of issues raised by the wider sub-set.

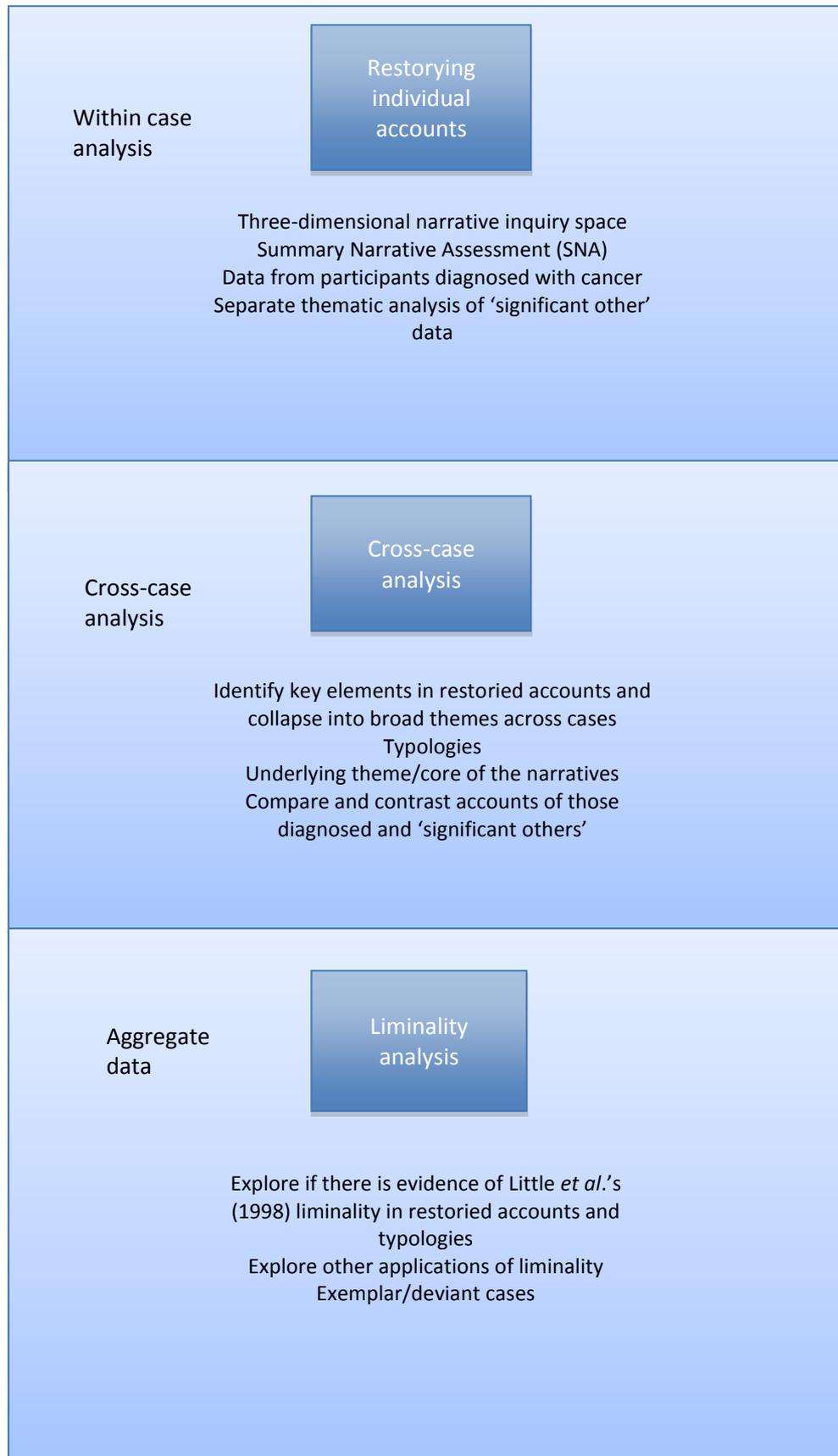
expect multiplicity, acknowledging that explanations would come from participants who met a particular pattern as well as those who did not. Accepting that associations were unlikely to be universal and that, therefore, there was a need to identify deviant cases, was also important (Ritchie *et al.* 2003b).

A summary of the analytical process is shown in Figure 5.10.

Generalisability

The concept of 'situated truths' in narrative research suggests it is not possible to generalise findings to a wider population (Riessman 1993, Holstein and Gubrium 1995, Pelusi 1997, Clandinin and Connelly 2000, Wengraf 2001, Andrews 2008, Riessman 2008). Case study research also does not aim to generalise findings (Stake 2006). However, Stake claims that if the reader relates to the case (through their own experiences, etc.) this can lead to a 'natural basis for generalisation' (Stake, 1978: 5 cited in Lincoln and Guba, 1985: 120). Equally, Stake refers to the fact that although case study research seems a poor basis for generalisation, in multiple-case study research certain themes are likely to repeat themselves within and across cases therefore some generalisations can be drawn - what he refers to as 'petite generalisations' (Stake 1995). Stake suggests that more 'formal' (or 'propositional') generalisations should really be referred to as 'hypotheses and working positions' (Stake, 2006: 89) as we can never know the 'truth'. He also refers to these as tentative assertions. Lincoln and Guba (1985) prefer the term 'working hypothesis'.

Figure 5.10: The analytical process



This study was exploratory in nature, therefore did not seek to generalise findings to the wider population of individuals living long-term after a cancer diagnosis. Crouch and McKenzie argue 'it is in the nature of exploratory studies to indicate rather than conclude' (2006: 492). However, it is necessary to build on exploratory studies in order to move the evidence base forward (Crouch and McKenzie 2006). As such, studies need to be 'embedded in fields of relevance that are tended by communal knowledge-building labour' (2006: 496). With this in mind, whilst I hope my research improves the lives of those living long-term after a cancer diagnosis, I am not under the illusion that one exploratory study will change policy and practice. I take the 'longer view' (Walt 1994). It is my intention to disseminate findings as widely as possible, engaging with policy and practice, the research community and individuals affected by the disease. However, to influence policy and practice, in particular, will take 'the cumulative weight of a line of research' which will eventually 'percolate' into the thinking of policy makers and practitioners (Walt, 1994: 234). That 'cumulative weight' of evidence on long-term survivorship does not currently exist, in the UK at least. It will therefore take time, and further research, to build that evidence base, and ultimately influence policy and practice.

Presenting the findings

The findings are written up in what Van Maanen refers to as a 'realist tale', which is a 'direct, matter-of-fact portrait' of events/experiences (1988: 7). This approach is advocated by Stake (1995). However, the realist tale does not adequately reflect the subtle realist perspective that accounts may be one of many possible 'tales' (Hammersley 1992). Nor does it acknowledge the researcher's role in the interpretation and representation of findings (Riessman 2008).

As such, a 'confessional tale' has also been weaved throughout the thesis (Van Maanen 1988). Confessional tales highlight the researcher's perspective, including difficulties encountered, the impact of the research on the researcher, methodological limitations, etc. – anything that may impact on the interpretation of findings. Therefore, in the confessional tale, the researcher adopts a reflexive approach and acknowledges that the 'tale' produced is one of many constructed representations of the social world being studied.

Quality in qualitative research

A 'bewildering' variety of concepts to assess 'quality' arose with the rise of constructionism, in response to the positivist/realist critique in qualitative research (Seale 1999). There is considerable debate as to whether the quality criteria used to judge quantitative research (for example, reliability, external and internal validity and generalisability) can be applied to qualitative research (Mays and Pope 2000). Lincoln and Guba's reformulation of these criteria to assess the 'trustworthiness' of qualitative claims fuelled this debate (Spencer *et al.* 2003). They argue that the 'conventional criteria' used to assess the quality of qualitative research are inappropriate. Crucially, objectivity is not possible (or desired) in qualitative inquiry because the research is value-laden. Instead, the importance of a reflexive approach is highlighted. Emphasis is placed on criteria that help 'persuade' the reader of the trustworthiness of findings (Lincoln and Guba 1985). As such, a reflexively-based evaluation of the quality of my research is presented here.

Reflexivity

Subtle realists argue that there are multiple representations of phenomena (Hammersley 1992, Hammersley 2002). I believe researchers arrive at these

representations through their interpretation of participants' stories (which are themselves interpretations of events and experiences). To do so requires researchers to 'make use of personal and cultural frames of reference' (Thomas, 2010: 651). Researchers therefore need to locate themselves as part of the data, exploring their role in data collection and interpretation. Thus, reflexivity on the part of the researcher is crucial to the trustworthiness of the representations constructed (Bishop and Shepherd 2011).

Reflexivity is not just the acknowledgement and identification of one's place and presence in the research, but also the process of using these insights to critically examine the entire research process in order to demonstrate the credibility of the study (Underwood *et al.* 2010). According to Bishop and Shepherd (2011), 'being reflexive and providing these reflections for public scrutiny is often considered a key element of ethical, rigorous qualitative research' as it enhances researcher transparency (2011: 1283). They go on to say, 'reflexivity is particularly valuable to qualitative research because it brings honesty to the fore, asking us not to feign objectivity or reach post-hoc conclusions, but to acknowledge that multiple factors, including our own personal narratives, shape the data we produce and our interpretations of this data' (Bishop and Shepherd, 2011: 1285). We need to be 'completely honest about the situated, co-constructed nature of our research findings' (2011: 1285). Highlighting decisions and thought processes over time increases the credibility of research (Anspach 1993). Anspach provides a 'narrative account' of the decisions made in her research (1993: 182). This audit trail fosters 'ongoing reflexivity – critical awareness about how the research was done and the impact of critical decisions made along the way' (Riessman, 2008: 191).

Figure 5.11 outlines Green and Thorogood's (2004: 195) suggestions for achieving 'reflexive awareness'. Using these strands I have produced a 'narrative account' of my research practice (see Chapter 10).

Figure 5.11: Reflexive awareness

Methodological openness – being explicit about the steps taken in the data production and analysis, the decisions made, and the alternatives not pursued

Theoretical openness – the theoretical starting points and assumptions made should be addressed, and the ways in which they shaped the study accounted for

Awareness of the social setting of the research itself – in interviews, the “data” are largely the results of interactions between the researcher and the researched. Reflexivity requires a constant awareness of this, and the ways in which the data result from these particular interactions.

Awareness of the wider social context - this might include awareness of how political or social values have both made possible the research and constrained it, and how the historical and policy contexts shape the data.

(Source: Green and Thorogood, 2004)

Summary

This chapter has sought to outline, and justify, the research approach taken. A subtle-realist perspective underpinned this study, which acknowledges that although a reality exists independent of our understanding of it, because knowledge is a human construction, there are multiple representations of that reality. The study explored, both individually and collectively, the experiences of thirteen individuals who were at least five years post-cancer treatment and their ‘significant others’. This was achieved through adopting a multiple-case study design, collecting data through narrative and semi-structured interviews. I took a story-analyst approach to the analysis. However, whilst I did not analyse the structure of the narratives, I was interested in both the ‘whats’ of the stories told (i.e. the content of the narratives), the ‘hows’ of the interview interaction (micro context) and wider socio-cultural and historical influences (macro context). I ‘restoried’ the narratives told, but reflexively explored the intersubjectivity between myself and the participants, thus acknowledging my part in, and influence on, the

stories and interpretations presented. I then used the 'restoried' accounts to conduct a cross-case analysis to 'merge' case findings to describe the experience of long-term cancer survivorship at the aggregate level. Using the 'restoried' accounts and cross-case analysis, I went beyond description, to explore the applicability of liminality as a framework for understanding experiences of long-term cancer survivorship. Finally, in an attempt to persuade readers of the trustworthiness of my research, I have outlined my intention to provide a reflexively-based evaluation of quality in the Discussion (Chapter 10).

Chapter 6. Profile of study participants

Tables 6.1 to 6.3 outline the basic socio-demographic and cancer-related characteristics of the thirteen individuals living five years or more post-treatment and the eight 'significant others' who participated in the study.

Socio-demographic characteristics

Nine women and four men took part in the study. The age range of participants was 39 to 75. Eight participants were married, one was in a civil partnership, one was in a long-term relationship and three were divorced. The ten participants who were in long-term relationships at the time of interviews were with the same partner they were with when diagnosed. Of those who were divorced, one was divorced prior to their cancer diagnosis, and the other two divorced afterwards. Ten participants had children. Of those, six had adult children at diagnosis (over the age of 18), three had children under the age of 18 (two with children under the age of 10) and one had children post-treatment. Four participants were employed (three full-time and one part-time), five were retired and four were what I have described as 'semi-retired'. They had retired from their main full-time job, but continue to work part-time in another role.

All participants lived in London or the South-East of England. The socioeconomic status of participants was derived from the Index of Multiple Deprivation, a widely used measure of deprivation. Based on Local Super Output Area (LSOA²⁸) figures (1= most deprived, 32482 = least deprived), the majority of participants lived in the least deprived 50% of LSOAs in England (n=9), with two participants living in the least deprived 10%. No one lived in

²⁸ LSOAs are geographical areas devised to be of a consistent size generated in a consistent way across the whole of England. The total population of LSOAs averages 1,500 people. These areas are nested, as far as possible, within electoral wards.

the most deprived 10% of LSOAs. Therefore, the socioeconomic status of participants was relatively homogenous, with the majority living in relatively affluent areas.

Cancer-related characteristics

Of the thirteen participants, four had been diagnosed with breast cancer, four with gynaecological cancers (two women with cervical cancer and two with ovarian cancer), two with prostate cancer, one with testicular cancer and two with colorectal cancer. No individuals diagnosed with bladder cancer or Hodgkin's Lymphoma came forward to take part in the study, despite approaching cancer organisations associated with these cancers. Five-year survival rates for these cancers are over 60%, but incidence is small in comparison to breast, prostate and colorectal cancer (10,335 cases of bladder cancer and 1730 cases of Hodgkin's Lymphoma in 2008 compared to 48,034 cases of breast, 39,991 cases of colorectal and 37,051 cases of prostate cancer)²⁹. As breast, colorectal and prostate cancers survivors account for over half of all survivors, it is not surprising that over half the participants in this study had been diagnosed with one of these three cancers (n=8).

The age range at diagnosis was 28 to 63. Time since treatment completion ranged from five to sixteen years³⁰. Eleven participants had some form of surgery. Seven had chemotherapy and six had radiotherapy. Two participants also had brachytherapy (cervical and prostate cancer). Five participants stated that they had some form of hormone therapy: Tamoxifen or Arimidex for breast cancer and Casodex for prostate cancer. It would have been useful to collect data on stage of diagnosis to ascertain how advanced each participant's cancer was. Stage of diagnosis and treatments received were

²⁹ <http://info.cancerresearchuk.org/cancerstats/> [Accessed November 3rd 2011].

³⁰ Time since treatment completion was calculated as the time since the end of active, hospital-based treatment to the time of the interviews - not the present date.

based on participants' recall and they often could not remember the specifics of their diagnosis.

Ten of the thirteen participants were involved with cancer organisations at the time of interview. By this, I mean they continued to access information and support services, or volunteered/fundraised for a cancer charity. Five participants were involved in cancer charity user involvement e.g. participating in research, campaigning activities or reviewing literature. Two participants worked or volunteered for a cancer charity, providing support to people affected by cancer. One participant ran a local cancer support group and another continued to use a charity's online forums as a source of information and support.

Conduct of interviews

The majority of participants found out about the study through cancer charities or a local cancer support group. No one was specifically recruited through snowballing i.e. no one participated then told someone else who then took part themselves. However, three participants heard about the study through word of mouth. One participant was told about the study at a separate meeting with one of my supervisors. Another found out about the study after they were told about it by a friend and a third came forward after an acquaintance working at a cancer charity told her about it. Finally, one participant came forward after seeing the flyer outlining details of the study after it had been sent to her place of work.

In total, thirty-one interviews were held. This included thirty individual interviews: twenty-three interviews with participants who had been diagnosed with cancer (twelve narrative and eleven follow-up interviews) and seven individual interviews with 'significant others'. I also conducted one joint interview with (with no follow-up interview). Initial narrative interviews

ranged in length from just over half an hour to nearly two hours. The average interview length was 1 hour 11 minutes. All but one of the participants took part in a follow-up interview³¹. These ranged in length from 21 to 74 minutes. The average length was 45 minutes.

Nineteen interviews were conducted face-to-face and twelve by telephone (predominantly 'significant other' and follow-up interviews). The initial narrative interviews were all conducted face-to-face, apart from the interview with Janet, which was conducted by telephone as she lived outside the study catchment area. The joint interview was conducted face-to-face and lasted 1 hour 15 minutes.

Eight 'significant others' agreed to take part in an interview. Five participants did not nominate a 'significant other' either because they could not, did not want to, or the person they would have nominated did not want to, or could not, take part. Seven of the 'significant other' interviews were individual interviews. The other interview, with Rachel, was a joint interview with Andy as already mentioned above. Of the eight 'significant others', five were spouses (three husbands and two wives), two were daughters and one was a friend. The 'significant other' interviews ranged in length from 8 to 55 minutes. Excluding the eight-minute interview with George, the average length of the 'significant other' interviews was 38 minutes.

Face-to-face interviews took place at a variety of locations. Based on School of Health Sciences guidelines on lone working and discussions with my supervisors, and as outlined in the ethics application to the Faculty of Medicine and Health Sciences at the University of Nottingham, it was deemed medium/high risk for me to conduct interviews in people's homes. Therefore, I planned to conduct interviews in public locations, unless circumstances

³¹ Malcolm was unavailable to take part in a follow-up interview because after our first interview he was travelling abroad for work, and spending the summer overseas with his family.

meant it was not possible to conduct the interview outside the home. In the event, interviews were held at the homes of five participants. These individuals were known to other cancer organisations, through their volunteer or user involvement activities. If the participant had been vouched for by another organisation or individual, it was deemed less of a risk for me to go to their home. However, processes were still in place to ensure my safety (as outlined in Chapter 5: Methods). The remainder of the interviews took place in participants' workplaces or community settings such as serviced meeting rooms.

Commentary on the adequacy of data collected

To enable depth of understanding in case study research, previous research suggested twenty as the maximum number of cases (Stake 2006). Thirty people contacted me to register their interest in taking part. Therefore, seventeen people were not recruited to the study. The breakdown as to why is presented below:

- One woman left a voicemail registering her interest but did not provide her contact details
- Four people said they were interested but when I attempted to contact them, I did not get a response
- Four people were not eligible because they were out of the study catchment area (North of England, Scotland, Midlands)³²
- One woman was not eligible because she was not five years post-treatment
- Four women with breast cancer were not eligible because they had a second cancer, recurrence or metastatic disease

³² I made an exception for the last interview with Janet, who lived in Cambridgeshire, as I was eager to interview a female diagnosed with colorectal cancer and she was the only one who came forward.

- Three women contacted me (two diagnosed with ovarian cancer and one with breast cancer) but I had decided to put recruitment on hold for those cancers as I had already interviewed eight women with breast and gynaecological cancers. At that stage I was looking to recruit men or women diagnosed with other cancers

Explanation for the discrepancy between the original target of twenty cases and the reality of thirteen also lies with the recruitment strategy. The number of people contacting me peaked between August 2010 and January 2011. After that I did not receive many calls from people interested in the study. Those that did contact me tended to be women who had been diagnosed with breast or gynaecological cancers, of which I had already recruited several. I focused on colorectal, bladder and Hodgkin's Lymphoma, targeting charities specialising in these cancers. However, recruitment continued to be slower than anticipated and it was only in May 2011 that Janet, a female colorectal cancer participant came forward. I continued targeting groups until June 2011. At this point, contact with potential participants had slowed further, I had exhausted charity options and community groups were not engaging so I decided, for both pragmatic and practical reasons, to stop at the thirteen cases I had recruited. In terms of the significance of the discrepancy in case numbers, I believe stopping at thirteen cases allowed me the scope to include more data and in-depth discussion of each case and therefore do justice to the accounts shared.

Regarding the length of interviews, I had envisaged they could last up to two hours. I proposed this length of time based on previous narrative research studies. However, when I started the interviews, it quickly became apparent that some would last longer than others. Some participants found the narrative approach relatively easy to engage with and were able to talk at length. Others were expecting a more traditional question and answer-type interview and found it difficult to formulate their narrative without support and guidance from me. Also, it is important to note that whilst several

participants were still active in the cancer community, this did not necessarily mean that they were well-versed in sharing their experience of living long-term after a cancer diagnosis. Some were, but others acknowledged that they had not spoken about their experiences for some time. For people like Janet, participating proved to be a useful experience in this respect as it allowed her to talk through some of her fears with someone who was removed from her personal situation. As the interview process evolved, I used the follow-up interviews to focus specifically on the long-term survivorship phase. The follow-up interview was therefore more a 'question and answer' interaction and only lasted 45 minutes on average. Also, if participants struggled in the narrative interview, I drew on questions from the follow-up interview schedule, which meant the follow-up interview was understandably shorter.

Some of the interviews were conducted in participants' work places. These interviews tended to be shorter, which is perhaps understandable considering the environment. Some of the longer interviews were those conducted in people's homes (Richard – 2 hours and Patricia 1 hr 45 mins and 1 hr 35 mins). This might suggest that location affected the interview length. However, Margaret's narrative and follow-up interviews were in a coffee shop and both lasted an hour and fifteen minutes. I would suggest that perhaps time pressures in the work environment had more of an effect on the interview length than the location itself.

Further discussion of the advantages and disadvantages of conducting interviews in the home is presented in Chapter 10.

Table 6.1: Overview of participant socio-demographic and cancer-related characteristics

Gender	N
Female	9
Male	4
Age range	
30-39	1
40-49	1
50-59	3
60-69	7
70-79	1
Employment status	
Employed full-time	3
Employed part-time	1
Semi-retired	4
Retired	5
Socio-economic status	
Least deprived 50% of LSOAs	9
Most deprived 50% of LSOAs	4
Least deprived 10% of LSOAs	2
Most deprived 10% of LSOAs	0
Marital status	
Married/civil partnership	9
In a relationship	1
Divorced	3
Children	
Adult children (18+)	8
Children under 18	2
No children	3
Cancer-type	
Breast	4
Gynaecological	4
Prostate	2
Colorectal	2
Testicular	1
Cancer treatment	
Surgery	11
Chemotherapy	5
Radiotherapy	5
Chemo radiation	1
Brachytherapy	2
Hormone therapy	5
Time since treatment completion	
5-6 years	5
8-10 years	3
10+ years	5
Age at diagnosis	
20-29	1
30-39	1
40-49	4
50-59	6
60-69	1
How they heard about the study	
Cancer charity work/volunteering	2
Local cancer support group	1
Cancer charity user involvement	5
Using a cancer charity for information and support	1
Word of mouth	3
Recruitment flyer	1

Table 6.2: Detailed socio-demographic and cancer-related characteristics of participants diagnosed with cancer

CASE	Name	Cancer	Gender	Age	Employment status	Marital status	Children	Age at diagnosis	Years post-tx at time of interviews	Treatments received	Cancer involvement	How did they hear about the study?	No. of interviews	Interview location(s)
1	Sue	Ovarian	Female	50-59	Employed, part-time	Married	Adult children	40-49	14	Hysterectomy, chemotherapy	√	Cancer charity	2	2 F2F at work
2	Mary	Ovarian	Female	60-69	Retired	Married	Adult children	50-59	7	Hysterectomy, chemotherapy	√	Local support group	2	2 F2F at home
3	Claire	Cervical	Female	30-39	Employed, full-time	Long-term partner	None	30-39	5	Surgery - trachelectomy	√	Flyer	2	2 F2F at work
4	Kate	Cervical	Female	50-59	Employed, full-time	Divorced	Child under 18	40-49	7	Chemo radiation, brachytherapy	√	Cancer charity	2	1 F2F, community setting; 1 telephone
5	Roger	Prostate	Male	70-79	Semi-retired	Civil partnership	None	60-69	11	Prostate removed, radiotherapy 1 year later	√	Cancer charity user involvement	2	1 F2F community setting, 1 telephone
6	Richard	Prostate	Male	50-59	Semi-retired	Married	Adult children	50-59	5	Hormone therapy, radiotherapy and HDR brachytherapy	√	Cancer charity user involvement	2	1 F2F at home, 1 telephone

7	Margaret	Breast	Female	60-69	Retired	Married	None	40-49	16	Lumpectomy, radiotherapy, hormone therapy	x	Snowballing	2	2 F2F in community setting
8	Patricia	Breast	Female	60-69	Retired	Divorced	Adult children	50-59	9	Mastectomy, chemotherapy, radiotherapy, hormone therapy, reconstruction	√	Cancer charity user involvement	2	2 F2F at home
9	Angela	Breast	Female	60-69	Semi-retired	Divorced	Adult children	50-59	6	Lumpectomy, radiotherapy, hormone therapy	x	Snowballing	2	1 F2F at home, FU by telephone
10	Moira	Breast	Female	60-69	Retired	Married	Adult children	40-49	16	Mastectomy, hormone therapy	√	Cancer charity user involvement	2	1 F2F community setting, FU by telephone
11	Andy	Testicular	Male	40-49	Employed, full-time	Married	Children under 18	20-29	15	Surgery	x	Snowballing	1 (joint)	F2F at home
12	Malcolm	Colorectal	Male	60-69	Semi-retired	Married	Adult children	50-59	7	Surgery, chemotherapy, stoma reversal	√	Cancer charity	1	1 F2F, community setting
13	Janet	Colorectal	Female	60-69	Retired	Married	Adult child	50-59	6	Surgery, chemotherapy	√	Cancer charity	2	Both interviews via telephone

Table 6.3: Characteristics of 'significant others'			
Name	Relationship	No. of interviews	Interview location
Peter	Husband	1	Telephone
George	Husband	1	F2F at home
Sheila	Wife	1	F2F at home
Geoff	Husband	1	Telephone
Amy	Daughter	1	Telephone
Penny	Friend	1	Telephone
Lucy	Daughter	1	Telephone
Rachel	Wife	1 (joint with husband)	F2F at home

Chapter 7. 'Restoried' accounts of the experience of long-term cancer survivorship

Introduction

This chapter presents case studies of the cancer experiences of the thirteen study participants. The objective was to develop detailed case study write-ups for each participant, describing their personal experiences of long-term cancer survivorship. As outlined in Chapter 5 (Methods), I adopted a holistic-content approach to the 'restorying' of participants' experiences, underpinned by the three-dimensional narrative inquiry space (Clandinin and Connelly 2000) (See Figure 5.8, p. 156). To facilitate the 'restorying' of accounts, I adopted Hall's (2011) summary narrative assessment template (Appendix 15), which allowed me to pull out broad themes from the narratives. These broad themes were used to structure the cases, supported by unique, detailed examples from the individual narratives. The cases include a short participant biography, outlining socio-demographic and cancer-related characteristics. I then present my interpretation of who the participant is today in relation to their cancer experience; participants' thoughts on the concept of being a 'cancer survivor'; relationships, interaction and communication; and day-to-day living. I conclude each case with a summary of the individual's cancer experience.

Sue's story

Sue (first interview): I suppose I get tired, I still call it "chemo fever", because sometimes I just drop. It's much better than it was, but I think it's just come to a level now where I just have to live within my boundaries really.

Sue was in her early 40s when she was diagnosed with ovarian cancer. At the time of her diagnosis, she was married, had teenage children and was working full-time in healthcare. Sue had a hysterectomy and chemotherapy. She took hormone replacement therapy (HRT) but decided to stop, as she was concerned about the risk of developing breast cancer. Sue attended follow-up appointments for over ten years, but made the decision to stop going. At the time of our interviews, Sue was in her mid-50s, and nearly fourteen years post-treatment. Still married, her children are grown up, and she works part-time for a cancer charity.

Who is Sue today?

Sue's narrative is set within the context of her support role at a cancer charity. Her experiences at work form a substantial part of her narrative. It seems Sue grapples with feelings of failure and guilt, whilst simultaneously working for an organisation where she has to maintain a positive outlook and listen to difficult stories that remind her that she too had been diagnosed with cancer. However, Sue said that, over time, she has come to realise that there is a purpose behind her diagnosis. Sue said she is now able to help others because she has both the medical and personal experience of ovarian cancer.

Uncertainty permeates Sue's narrative, which stems from past decisions – declining a clinical trial and questioning whether she should have had chemotherapy – and concerns for the future – risk of recurrence, the impact of ageing and other health conditions on her ability to participate in the activities she enjoys (such as walking) and her daughter's risk of developing cancer. Sue acknowledged that she has always been a pessimist. In this respect, it seems she cannot allow herself to be positive about the future. Sue said that she does not think she will live as long as she once expected, is probably vulnerable to other cancers, and has to '*live within her boundaries*' as a result of what she referred to as '*chemo-fever*' (fatigue). However, she also said that she feels fortunate to have been diagnosed early, that

she is '*probably cured*' and therefore needs to pace herself, as she has to be well enough to deal with life. It seems she wants to be cautiously optimistic about the future, but her pessimistic outlook on life, coupled with the cancer stories she hears, prevents this.

Sue (first interview): I probably think that my future isn't going to be as long as I would have maybe thought about in the past. I think there's probably long-term implications of having treatment and I probably think I'm probably more vulnerable to getting other types of cancer. So, I don't see that I'm going to be around until I'm 100.

Sue comes across as hard on herself, particularly when comparing herself to others. She said she is '*ashamed to say*' that she has not changed as a result of her diagnosis, saying '*it's very difficult to change how you've always been*', as if changing who you are is what is expected of someone diagnosed with cancer. Sue also alluded to feelings of survivor guilt. For example, she stopped attending follow-up appointments because she felt guilty going to clinic when she was ok but others were clearly very sick. She may also feel guilty when listening to the experiences of other women affected by ovarian cancer. As Sue said, she was fortunate her cancer was diagnosed early. Many of the women she speaks to have not been so fortunate. She mentioned that women with advanced ovarian cancer do not want to hear the experiences of those with early stage cancer (such as herself) as they perceive that those diagnosed early have a good prognosis from the start. Women with more advanced disease often make it clear to Sue that they only want to hear about women who have done well after a similar diagnosis.

Perception of the concept of 'cancer survivorship'

Sue said she thinks people still see her as a person who has had cancer, and that people who have been diagnosed are '*labelled for a long time after*'. She does not identify with the term 'living with cancer' as she feels she does not have cancer anymore. However, she thinks people requiring further treatment are 'living with

cancer'. She said it is difficult to get the terminology right. 'Survivor' suggests she has done something to make herself a survivor, but Sue is not sure she has done anything more than anyone else would. To her, when people say 'survivor' it sounds like they have *'done an awful lot. And some people have done, but for other people it hasn't made any difference to how they've been'*.

Sue acknowledged that cancer is a *'horrible, horrible thing'*, but she has *'been there'* and is *'ok'*. As such, she maintains that people with cancer do survive, and as result there is hope. In contrast, she thinks there is no hope with neurological, progressive diseases like motor neurone disease and arthritis, as they are debilitating conditions. Despite this, she feels cancer is perceived by most people to be the worst thing in the world. She said, *'I'm just aware that cancer seems to be on a pedestal'*, going on to say, *'it's got this terror'*. She said the media compounds this *'terror'*, portraying cancer as a battle that everyone has to fight and, if you do not fight, you will not win.

Relationships, interaction and communication

Sue continues to feel a certain amount of pressure to put on a *'façade'* for some people. She said, *'I do get tired. But for certain people I will have to put on a façade, yeah, and just say, "everything's alright" because all that they really want to know is everything's alright as far as the cancer's concerned'*. This façade is linked to what she feels is society's aversion to bad news, and a need for *'positivity'*. She said that people cannot cope with her not being well, partly because they feel guilty that they are ok and she is not. As a result, she feels she has to be careful what she says to people, for their benefit. Sue also feels that many people still think that everybody diagnosed with cancer dies, and that if you do not die, then you did not have cancer in the first place:

Sue (follow-up interview): ...if you've got cancer, you know, "wow", it gets an awful lot of attention and in a way that can make things difficult because people focus on what's

happened to you, inquisitive and a bit, wanting to know exactly the ins and outs and imagining that you're going to die. Cos most people think cancer equals death.

EB: And do you think that's why it has the profile that it does, because people do still think, cancer equals death?

Sue: Yeah. You ask most people down the street and they will say that most people with cancer die. So I stand there [laughs] and say "I'm still here". Yeah I have been in conversations where people have said "oh well everybody with cancer dies" and I "ooh, well actually" [laughs]. Or they think, and actually this is a very vivid memory, that because you've done alright, that you didn't actually have cancer in the first place. Or it wasn't proper cancer. That was very strong memory. People were thinking "oh you're alright, but you only had weak chemotherapy". I remember one friend saying "oh yes but you only had weak chemotherapy". Aaargh, you know... I think there's quite a bit of doubt that if you're doing ok, you didn't actually have it properly in the first place.

Day-to-day living

Sue has to be careful about how much she takes on, as her stamina levels are quite limited. She described how she gets tired easily, referring to this as '*chemo-fever*'. She can only work part-time and if she pushes herself too hard, she becomes unwell. As such, Sue described being a '*little obsessional*' about the spread of the '*dreaded lurgy*'. Sue is now more aware of anything that is wrong with her, and that things could '*still go wrong*' i.e. recurrence. However, if she has an ache or pain now, cancer is not the first thing she thinks of: '*I think somebody said to me "you will think every ache and pain is the cancer coming back for at least five or ten years" you know? Whereas now, it has to be there for at least a week or so before I do anything about it*'.

Sue (follow-up interview): ...now it's not a big issue for me really. Most of the time. You know, you obviously get the odd moment when you think, or if you have a particular ache or pain, you think, "ooh what's this all about?"

Summary of Sue's experience of long-term cancer survivorship

Fourteen years post-treatment, Sue's life, and that of her family, is still very much consumed by cancer. She has to *'live within her boundaries'* as a result of her diagnosis. The nature of her work at a cancer charity means she sometimes relives her experiences through the stories she hears. However, the benefits of her role include feeling that there is a purpose behind her diagnosis and a *'rational knowledge'* of ovarian cancer stops her worrying as much as she might otherwise. Her diagnosis, and subsequent employment, has also deepened her relationship with her husband. As a result of the stories Sue hears, coupled with her pessimistic nature, the future is one of contradiction and uncertainty.

EB (follow-up interview): So [cancer is] not really at the forefront of your mind?

Sue: Well, people say, it's very difficult because working here, I'm thinking about it and it's all a mixture really, where I come in and where I go, and the cut off period, so it's quite difficult to say what it would be like if I wasn't working here, or how much I'd be thinking about it.

Sue (first interview): ...it's been filed away somewhere. I don't know how I would be if I wasn't in this job, you know, because I've got some sort of rational knowledge of it all, rather than if say I wasn't involved in this, I maybe would be more worried about what might happen in the future.

Mary's story

Mary (first interview) ...although I'm optimistic by nature, I am sort of on borrowed time, so each year is a bonus. I would like to forget about having had cancer, and that's not denying that I've had cancer... But there are times when I would, if I'm being honest, I'd like to be really shot of anything to do with cancer.

Mary was in her late 50s when she was diagnosed '*out of the blue*' with ovarian cancer. At the time of her diagnosis, she was married, with adult children and working part-time in healthcare. Mary had a hysterectomy followed by chemotherapy. At the time of our interviews, Mary was seven years post-treatment. She was in her mid-60s, still married, and now a grandmother. Mary retired two years after her diagnosis but carried on working on an ad-hoc basis for a further five years. She is actively involved in a local cancer support group and cancer experience panel at her local hospital.

Who is Mary today?

Mary said she has had a '*very happy and privileged life*' and that sums up the tone of her narrative. She is a positive, pragmatic woman who values the moment and lives in the present.

Mary (follow-up interview): ...life is very precious and it's not guaranteed anymore. And initially I thought I probably wouldn't last a year or two, so in that sense I feel it's borrowed time, but I'm not thinking I've got to, it's not affecting how I function, in so far as thinking this is my last day. It's just I'm very grateful for still being here and still feeling well.

Mary does not feel she has changed as a result of her cancer diagnosis. She said that life events prior to her diagnosis have affected her more. Close friends of her family died in an accident, which made her appreciate the value of life. However, Mary admitted that life busier than ever, even though she has retired. She attributes this to being heavily involved in cancer activities and suggested she needs to cut down her involvement. She runs a support group - something she feels responsible for and therefore cannot extricate herself from. She wants to do more for herself, so-called '*selfish*' things, like hobbies, but feels guilty if she engages in such activities. She admitted cancer features too heavily in her '*general day*' and

acknowledged *'I've got to come to terms with sorting that out, cos that's not the right balance.'*

Mary (follow-up interview): ...I'm very involved in the cancer field... I'm very, very involved and life actually feels more pressured now, because of the cancer involvement, and I get to the stage where I feel guilty now if I'm doing something, what I call, selfish.

However, Mary said sitting on the cancer user group is rewarding as she sees improvements at her local hospital. Indeed, Mary said her daughter is pleased she sits on the user group as it feels as though something positive has come out of a bad experience. She said that she would be just as busy with other voluntary activities if she were not so involved with cancer groups, because even though her family are important to her, Mary admitted she could not exist solely *'in our own unit.'*

Perception of the concept of 'cancer survivorship'

Mary trained as a nurse when cancer *'was an absolute taboo'*; people did not talk about it. She said cancer still has the *'instant death at any age'* association that perhaps is not associated with diseases like MS and Alzheimer's. Mary feels guilty about cancer's profile at the expense of other long-term conditions, particularly as she perceives other conditions to be worse than cancer.

In terms of the terminology used to describe people affected by cancer, Mary hates the idea of *'engaging in a battle'* because *'it's a reflection on people who it looks as though because they've died, that they haven't [battled]'*. She also dislikes the terms *'cancer survivor'* and *'sufferer'*. She said *'I feel that I've had cancer, it's an illness, and I'm just lucky that I'm well. I think I call myself well, rather than a survivor'*. However, Mary said that even though she does not consider she has cancer anymore, she is conscious that she has had it, and is probably more likely to have it

again than not. As such, she said she is looking at death in a more vivid way and, consequently, feels she is living on '*borrowed time*'.

Mary (follow-up interview): ...certainly each year is a milestone. And although I don't consider I have cancer now... I'm conscious that I've had it and so I feel I'm probably more likely to have to again than not.

Relationships, interaction and communication

Mary's narrative highlighted the underlying importance of her family. The most valued and important events in her life seem to have stemmed from family experiences. Indeed, her hopes for the future are framed in relation to her family. She hopes to continue to be a '*proactive grandparent*' and see all her children married. Mary feels the impact of cancer was worse for them:

Mary (first interview): I strongly feel it's worse for the relations than the person. Because you've got the diagnosis, you don't have a choice you've got to get on with it. The other people have got to deal with it themselves. They've also got to deal with how do they relate to the person with it, you know, what can they talk about what can they not, you know, how can they help, what mustn't they do, what mustn't they say. And I think that does create problems. You know, I think it is harder for them.

Mary feels no one responds to, or treats, her any differently today. She hopes her family think of her as someone who has *had* cancer, but also that they do not define her by her diagnosis. Mary thinks her children have become closer as a result of her cancer. She said that '*...seeing how the three children have sort of clung together and seem to be supporting one another and supporting my husband*' is a source of comfort to her.

Cancer has made Mary re-evaluate the importance of nurturing friendships; she now values friends and building friendships, which in turn has helped develop support networks for her children and husband – something she was keen to

achieve, as she wants to ensure they are able to function in the event of her death. Again, this demonstrates her pragmatic approach to cancer.

Day-to-day living

Mary said she would have ignored aches and pains in the past, but now she fears they could be cancer-related so acts on them. She gets a '*nagging feeling*' that certain pains could be a sign of recurrence. Indeed, at the time of our follow-up interview, Mary was undergoing investigations for a pain in her stomach. It was not a constant symptom but she wished she knew what was causing it. As a result of these '*reality checks*', Mary experiences a loss of certainty about health. This uncertainty seems to have been compounded by the lack of information she received on treatment completion about signs and symptoms of recurrence, and her involvement in cancer groups as she regularly hears of people being diagnosed with a recurrence. Mary also described a loss of certainty about her children's health. She worries she has passed on '*bad genes*' and is therefore influencing their chances of developing cancer.

Mary described herself as '*well*', and very healthy, otherwise. She can still participate in the physical activities she did prior to her diagnosis, for example, tennis. However, she mentioned that her tennis grip is not as strong.

Summary of Mary's experience of long-term cancer survivorship

Mary has a positive outlook on life. She is aware of how valuable life is, and therefore lives in the moment. However, cancer has a central place in Mary's life today, predominantly as a result of the cancer groups she is involved with, but also as a result of ongoing investigations for a pain in her stomach. As she did not experience symptoms around the time of her diagnosis, and is seemingly still unsure of signs of recurrence, Mary lives with an uncertainty about her health.

Although optimistic by nature, she said she is *'sort of on borrowed time, so each year is a bonus'* and feels she is looking at death in a more vivid way. This does not affect her daily living, but seeks to underscore how precious life is, and that is not guaranteed any more.

Claire's story

Claire (follow-up interview): ...I do just try and look at it as, yes, it was an awful time, it was total upheaval, a lot of people were very, very hurt and upset by everything that was going on. But it's done. It's done now... I think you have to get to that point where you do put a lid on it, lock it up and put it away and go "right, that's it. I have to now just get on with it and try not to let it consume me as much as it did."

Claire was in her early 30s when she was diagnosed with cervical cancer after a routine smear test. At the time of diagnosis, Claire was in what she described as a new relationship (she and her partner had been together for one and a half years), with no children. She was working full-time when she was diagnosed, and continues to work full-time today. Claire had a trachelectomy, the aim of which was to preserve her fertility. Her physical recovery took six months, during which time she suffered from post-traumatic stress disorder. At the time of our interviews, Claire had recently attended her five-year follow-up appointment, a *'milestone'* for her. She volunteers for a cancer charity, raising awareness about cervical cancer through media interviews. She is still with her partner and, by choice, they do not have children.

Who is Claire today?

Claire approached her diagnosis in a positive, pragmatic way, saying she would do whatever had to be done. The first two years were the most difficult for her; she described at length how cancer *'consumed'* her during a difficult post-surgery

recovery period. When she came out of hospital *'it hit me and I was like "this is quite major"'*. She described the period as *'full-on'*, and did not like being out of control. As a result, she suffered panic attacks that *'stunted'* her recovery. She talked at length about the lack of support she received from health professionals post-treatment. It was at this point that she drew on the support of her family. She feels that if her family situation had been different, she would have struggled even more than she did. As it was, Claire and her family *'muddled'* through and she overcame the panic attacks with the support of her GP and mum. The turning point in her recovery was going back to work, when she could *'get back into normal life as much as you can call it normal life.'*

Claire's age and life stage have played a part in shaping her cancer experience. She mentioned that it was overwhelming having to make decisions about treatment at such a young age. She was also in a relatively new relationship and found it difficult talking to her partner, not just about cancer, but about her fertility, and the possibility of having children in the future. Claire had to make a decision whether to have a hysterectomy or a pioneering trachelectomy. Initially, she wanted a hysterectomy because she wanted anything to do with the cancer removed so, in her eyes, the risk of recurrence was reduced. However, Claire was persuaded to go ahead with the trachelectomy. She did worry about recurrence, particularly in the first couple of years – questioning whether doctors had removed all the cancer. However, how she feels about her treatment has changed over time. She is reflective in her narrative, saying that when she passed the five-year marker, she came to realise that it was *'by the by'* which surgery she had - because she had survived. However, she lives with a degree of uncertainty because, as yet, there are no ten-year survival statistics for women who have had a trachelectomy as it is such a new procedure. She continues to worry about recurrence, particularly before follow-up appointments, but believes she now has the same risk as everyone else, back to *'one in three'*. Claire is pragmatic about the possibility of cancer recurrence, saying *'you go back statistically to how everyone else is then you go "well if I'm*

going to be dealt the card again, I'm going to be dealt the card again", but that's that.' She summed it up by saying: *'It was a very interesting time, don't ever want to go back there again.'*

Claire talked about how she feels she has changed for the better as a result of cancer, becoming less *'Miss OCD'* and able to walk away from situations that in the past she would have let bother her. However, when I asked her how she thought other people would describe her now, she said: *'The same as before. Miss OCD, weirdo, whatever. I think they'd all be sitting here going "shut up, you're as bad as what you were". If people actually remembered what I used to be like, I have changed, maybe just a little bit, but I have changed.'* Claire does not plan for the future, not because she feels there is no future to plan for, but because she thinks life is too short. She feels she has changed in this respect as she always planned and liked to be in control. She has *'put the reins on'*, and slowed herself down.

Perception of the concept of 'cancer survivorship'

Claire feels she reverts back to being a cancer patient at follow-up appointments, now once a year, but thinks of herself as a survivor as she has literally survived something that could have killed her. However, also evident in her narrative are examples of how she has survived the experience of cancer: surgery, her recovery, panic attacks and reaching the five-year marker she was clearly aiming for. She is proud of her survival. The idea of *'fighting'* resonates strongly with Claire. In this respect she does think of herself as a survivor, but would not necessarily refer to herself as such. She seems to have approached the experience with something akin to *'fighting spirit'* – *'my view was "what do we need to do about this?" We've got to do whatever we've got to do. I'm not going to die from this, you know, let's just get it done.'*

Relationships, interaction and communication

An underlying theme in Claire's narrative is the importance of family, highlighted by quotes such as: *'[cancer] corrupted my life and made my family so upset'; 'you've done this to me, and this upheaval for my family'*. Cancer was a family experience – one she feels was harder for them to go through. Claire used 'we' and 'us' several times in her account: *'that's where we struggled', 'I think [panic attacks] stunted everything and sort of threw us off course'*. She feels closer to her family, particularly her mum and sister, as a result of the support they gave her. Further evidence that cancer was a family experience, and one of great upheaval, is demonstrated by the fact Claire did not nominate someone to take part in a 'significant other' interview. She knew her mum would participate if asked, but Claire did not want her to have to relive the experience.

Claire (first interview): I still to this day say that I think it was harder for my family and my friends than what it was for me... I was the one that had been diagnosed so you just have to get on with it. Whereas, you know, to see your parents just wanting to solve the problem for you, as they do, and they couldn't, you know, it was heartbreaking really.

The importance of understanding is clear in Claire's narrative. She feels that unless you have been through the cancer experience, you will struggle to understand how she feels. Claire's partner, Craig, demonstrated a lack of understanding with respect to the importance of the five-year marker. He did not meet Claire's *'expectations'* and this has been a recent source of distress for her. When Claire was diagnosed, as she and Craig had only been together a short time, she said he could walk away if he wanted to. However, after many years together, and supporting her through the experience, she felt *'let down'* when he did not fully appreciate, or celebrate, the importance of the five-year *'milestone'*. Claire also talked about the importance of peer support, and in particular, her *'hospital friends'* as they *'know exactly how I*

feel'. She put this in context by saying that when her mum says "*oh I know how you feel darling*" Claire feels '*well, actually no mum, you don't.*'

Day-to-day living

Cancer does not seem to affect Claire day-to-day. She suffers from back pain and stomach ache from time-to-time but does not regard these as symptoms of a possible recurrence, more a side effect of surgery and a lack of fitness, which she is now addressing. She said these issues are nothing to complain about, comparing herself to others who are in a much worse situation.

Summary of Claire's experience of long-term cancer survivorship

Claire approached her cancer diagnosis with something akin to 'fighting spirit' and, whilst she clearly would not want to go through the experience again, described several positives as a result of her diagnosis. Claire noted positive changes to her sense of self and relationships. She now raises awareness about cervical cancer and the importance of screening, and gains valuable peer support from her '*hospital friends*' who she feels understand exactly what she has been through. As such, family and peer support have been key to enabling her to move through, and beyond cancer.

Kate's story

Kate (follow-up interview): I'm less ashamed. I used to be ashamed about what had happened to my body and I don't know yet if I accept what has happened to my sexuality, I wouldn't say I've accepted it.

Kate was in her early 40s when she was diagnosed with cervical cancer, after an abnormal smear test. At the time of her diagnosis, Kate was married, with a young child. She was refused surgery as she had an underlying medical condition, receiving chemo radiation instead. Her marriage broke down shortly after she finished treatment, which meant she had to leave her job so she could look after her child. At the time of our interviews, Kate was in her early 50s and seven years post-treatment. She attends annual follow-up appointments, which will continue for another three years. Kate is divorced, and has not had a relationship since diagnosis.

Who is Kate today?

It appears Kate is still coming to terms with her diagnosis, and its consequences. Kate referred to the consequences of cancer and its treatment as the '*legacy*' of cancer: '*cancer affects the whole way you feel about yourself as a person*'. Kate has accepted the impact of treatment on her bowel functioning. However, she admitted she has not fully accepted the impact cancer has on her sexual function and relationships. As she said, cancer threatens your '*whole world being*'

Kate (follow-up interview): ...having your life threatened is, yeah, it's the biggy isn't it? You can get through other things. This is beyond your control. And you're essentially very passive. You don't know the answers whereas you feel you can control your marriage break-up or control how you deal with it and the outcome. It's the powerlessness of cancer.

Kate said she sometimes thinks she will never have another intimate relationship, and has been avoiding the issue. She said this has had an impact on the way she feels about herself as a woman, and is yet to be resolved.

On reflection, Kate said she felt '*depleted as a person*' prior to her diagnosis. She now perceives herself to be a better friend, mother and daughter, as her priorities

have changed. Cancer forced that change, as she had to give up a busy job once her marriage broke down. Kate said that cancer has changed her priorities: *'people are number one... it's 100% about people.'* She feels she is a kinder, more confident person, and more respectful. She likes her life today, as she can spend more time on the things she values because she is not in such a highly pressurised, demanding job.

Kate's narrative made several references to fear. When we started the narrative interview, Kate said *'God, it makes me scared just thinking about it now.'* She mentioned that early on in her illness experience, she could not talk about follow-up appointments: *'I couldn't even bear to talk about it or admit that it was happening or say the word "cancer". I literally couldn't bear it.'* Follow-up appointments were *'really horrifying'* and *'absolutely terrifying'* as she felt she was being given her life in *'3-month segments... so most people you've got this horizon, you're whole life it's a limitless horizon, and mine was just fed to me in measly little chunks.'* She now attends one-yearly appointments and said *'obviously the fear recedes to an extent the further you go in'* but she said she still feels nervous. When I asked Kate if she worried about recurrence she emphatically said *'I do, I do, I do'*.

Kate smoked but gave up when she was diagnosed. However, she said that as the fear had *'worn off'*, she began smoking again, which results in *'enormous amounts of fear'*. She could not explain why she started smoking again but said *'it's mad and that terrifies me.'* Related to smoking, is a fear of God:

Kate (follow-up interview): ...if I'm smoking, I'm freaked out that God is going to punish me because I'm spoiling my gift of life that he's given me, by not making me die of cancer. I mean, I have this awful, biblical sense of doom and wrongdoing... It's totally overshadowing me and filling me with doom.

Kate said fear has receded over time, as *'time does its usual healing thing.'* However, ongoing issues, such as occasional blood in her urine, continue to cause

spikes of fear, which result in cancer having a constant, yet oscillating, place of in her life.

Perception of the concept of 'cancer survivorship'

Kate described herself as *'someone who's had cancer.'* She thought that, if asked, she would say *'I had cancer x years ago.'* She felt the term 'cancer survivor' was *'so much better than the bloody cancer victim thing.'* She said replacing 'victim' with 'survivor' was *'100% positive'*, and would use the term 'survivor' to describe herself. She went on to say *'I'm a survivor and I feel good about surviving. And I feel good about the fact that I didn't fall apart and I didn't go mad.'* To her, *'there's a few connotations of being proud of yourself, being a survivor, to me, it indicates a certain strength and courage, that you didn't crack up. So I view it very positively.'* In this sense, Kate described surviving the experience of cancer, as well as the disease itself.

Kate also touched on the 'battle' analogy, and being brave. She does not agree with the *'bravery stuff'* because *'you have no option but to be brave.'* She feels that being a survivor does not mean you have to do something extraordinary, it means you were one of the lucky ones. She likened being a cancer survivor to surviving a crash or a terrorist atrocity: *'you're not doing anything brave, you're just, you were there and you're lucky.'* We also talked about 'living with cancer', a term Kate is strongly against, referring to it as a *'horrifying expression of darkness because for me, I'm a survivor and I've left that behind. I hate that term'*. She said that people with incurable cancer are 'living with cancer': *'I've got a friend with either Hodgkin's or non-Hodgkin's Lymphoma and she's got the one that isn't going to go away, they can't cure it, but it doesn't kill her for 18 years. She's living with cancer.'*

Relationships, interaction and communication

Kate talked about the social unacceptability of cancer generally (equating cancer with death), cervical cancer specifically (*a 'dirty cancer'*) and the *'taboo'* side effects of treatment (related to bowels, bladder and sex). This perceived social unacceptability has influenced who Kate has told about her diagnosis. She is *'secretive'* about cancer with new people partly, she said, because it was a long time ago so there is no need to tell them, but also because she does not want to deal with others' perceptions of cancer generally (*'poor you'*) and cervical cancer specifically. She said she struggles to vocalise her concerns about sex and bladder issues with her friends, choosing only to talk to those who have personal experience of these problems. However, Kate said that she values friendships more today, and that she is a better friend. She is more thoughtful, but also more critical.

Kate's marriage broke down shortly after treatment completion. She said *'...it was a weak relationship, there were a lot of problems there.'* Therefore, it seems cancer itself did not cause the marriage breakdown, but it was a precipitating factor. Linked to marital breakdown, sex and relationships appear to be the abiding problems for Kate today; issues she feels she may never overcome. This has a bearing on her future, not just in terms of starting a new relationship, but how she feels about herself as a woman: *'I would say for anyone with gynae cancer, it's a huge, huge issue... I mean it's a major, major, major issue.'* There are a complex set of related issues to unpick regarding Kate's sexual function and relationship problems - the way Kate feels about her body in particular. For a long time, her lower body was not a part of her, a *'wasteland'*: *'You hate your body. I couldn't, I totally divorced myself from anything below the waist, mentally and physically. For ages I couldn't accept it as part of my body, that's stopped now.'* Kate also links sex with death because she feels cervical cancer was caused by the spread of human papillomavirus (HPV). As a result, she has trust issues, which prevent her from forming an intimate relationship. Kate's first experience post-treatment would be

with someone she does not know, so she wonders at what point she would tell him she had cervical cancer. This is linked to her concerns regarding other people's perceptions of cancer. Finally, in terms of her broader life context, Kate admitted she would be starting a new relationship as an older, single mother. Bringing these issues together, Kate acknowledged that she is avoiding the issue of sex and relationships.

Kate (first interview): I haven't slept with anyone since and that's going to be a huge issue. I don't know whether I ever will now. I sometimes think I never will. And it's partly because sex for me means death. It doesn't mean death, this is the, you know, it's a risk... So there's a huge trust level.

Day-to-day living

Kate described herself as a healthy, fit woman for her age, and ongoing issues she has regarding bowel and bladder function do not stop her from going about her daily life. She follows a healthy diet, avoiding fatty foods (which she learnt cause her bowel upset), and stays hydrated to prevent bladder problems and blood in her urine. However, her '*hyper-vigilance*', checking for blood in her urine every day, means cancer is a constant in her daily life.

Summary of Kate's experience of long-term cancer survivorship

Despite apparent gains to Kate's sense of self, outlook on life and relationships with friends, she does not agree that her diagnosis has resulted in any '*positives*' per se, as the following quote from her narrative shows:

EB (follow-up interview): So there are some positives as a result of a diagnosis of cancer?

Kate: No I wouldn't ever say there's any positives as we'd all much rather carry on being a bit crap and not having it. I wouldn't call it, positive is too strong a term but I

just mean, it so happens... I think it can be very good for your confidence, really, if you survive that level of bush-fire, well for me anyway, you know that really your worst nightmares have come true and you've got through it, that's how I feel. But I wouldn't recommend it.

Kate's life is clouded by the ongoing '*legacy*' of cancer and consequences of treatment, particularly regarding sexual function and relationships, and bowel and bladder functioning. For example, when Kate finds blood in her urine it '*always fills [her] with horror and fear and brings back the horrible fear*', which clearly highlights that fear is the underlying theme of Kate's narrative.

Roger's story

Roger (follow-up interview): ...I don't use the word "cured" by the way. I think that's the wrong word. Even if you've had prostate cancer and it's been treated, you're still living with it in the sense, some of the things you mentioned, like maybe incontinence or scar tissue because of a catheter or sexual things, you're still living with the effects of it.

Roger was diagnosed with prostate cancer twelve years ago. He was in his early 60s and working full-time. He opted for a prostatectomy. However, he experienced incontinence as a result, which limited his daily activities until he was referred to a specialist nurse who provided him with advice and support. At a check-up a year later, '*a dark cloud*' came – Roger's prostate-specific antigen (PSA) level was raised, so he subsequently had radiotherapy. As a result of his treatments, Roger has ongoing problems regarding sexual functioning, and during more recent operations for stomach and knee problems, scar tissue prevented catheterisation. Roger is in a long-term relationship with his partner who has been a key source of support, as has their faith. They entered into a civil partnership eight years after Roger's diagnosis. As a result of the ongoing consequences of treatment, Roger would not describe himself as '*cured*' but '*living with effects of cancer*'.

Who is Roger today?

Roger described himself as a Christian, and a believer. He talked about how his faith '*probably became stronger*', partly through the support he received from the church community during treatment. Roger said that an overseas trip he and Ian took post-treatment was an important turning point for him: it '*did wonders for me, wonders for my self-esteem, cos I was doing all the things, eating well, walking a lot, all that and sleeping a lot, it did wonders for my self-esteem.*' He said he appreciates life more. In particular, cancer has made him appreciate his friends, especially those who supported him and his partner through such a '*turbulent*' time.

Along with cancer, Roger said his age, sexuality and faith have '*moulded*' him into who is today, and shaped his view of life and death. He mentioned that if he were diagnosed today, he would opt not to have treatment, preferring to 'watch and wait'. Maintaining his quality of life at this stage of his life would be a more important consideration.

EB (follow-up interview): I just wondered, you said that cancer had been one of life's experiences that has moulded you into who you are. I was just wondering what other things have shaped you?

Roger: I think many things mould you to the person you are. I mean you talked of faith; that moulded me. I'm a gay man. That moulded me. And I think cancer moulded me as well. I'm much more aware now of my mortality, which obviously I didn't think much before. But I don't take the view that I'm living on borrowed time. Some people do you know? On the other hand, I've lived past my biblical benchmark, [laughs] so you know, you could say I've got bonus years. But as people are all living longer. But I do think it shapes you.

Perception of the concept of 'cancer survivorship'

Roger talked at length about the issue of whether someone can be cured of cancer, and how he would describe himself with respect to the disease. He does not believe he is cured, and therefore cannot say he has survived cancer. However, he does say that he has survived treatment. If asked, Roger would say that he had prostate cancer twelve years ago, but there are 'remnants' there after surgery. Initially, '*...it was me that opt for the operation because the others didn't seem um, so final... I thought well if they take it out, it's out, it can't come back again.*' However, as was described to him by his surgeon: '*although the prostate was out, and they'd got most of it, somehow remnants remained... and then it seemed logical cos I said to him "look, you've taken it away" but when you cut something, like when you're pruning a branch, you throw the old bit away but there's a bit of sap, then it begins to grow...*' As a result, Roger feels he lives with 'remnants' of cancer, does not believe he is cured and does not identify with the 'cancer survivor' label:

Roger (follow-up interview): I don't, I'm not against cancer survivor, it assumes again, you see, that you've been cured. And that's a bit of a problem I've got because, in all intents and purposes, the consultants and such, they cut it out, they treat you and you're cured. If you could turn the word round and don't see how you can, I'm living long-term with cancer or I've survived cancer, but not at the end, do you know what I mean? I suppose you survive the medical treatment, but you haven't survived living with it, I don't know how to put it into words.

Relationships, interaction and communication

The impact on Roger's sexual function is a long-term consequence of surgery and, although it is not such an issue today as, by Roger's own admission, he is older and therefore not as sexually active, he still uses aids to engage in sexual activity. Roger said his partner, Ian, has been very supportive and understanding, helping Roger make decisions regarding treatment and talking through the sexual problems Roger experiences. They have become closer as a result of Roger's diagnosis, entering into

a civil partnership during the long-term survivorship phase. Roger said this was 'purely mercenary', to ensure his estate goes to Ian, and that Ian is legally recognised as Roger's next of kin.

Day-to-day living

Other health issues have a greater impact on Roger's daily life than cancer and its long-term consequences. A knee operation was affecting his mobility at the time of our interviews. He also has a heart condition, which meant that when discussing options to aid sexual functioning, he could not take Viagra. Roger is positive about the future as he looks after his health, consulting his GP or consultant if he is concerned. However, he acknowledged that his future is limited because he is in his 70s:

EB (first interview): What does the future mean to you now?

Roger: Well when you're 75 your future's limited, um, I've already overstayed the biblical three years, what is it?

EB: Three score years and ten

Roger: (laughs) I still think I've got at least, I hope, another 10 years, um, I'm still active in all sorts of things... Um, so very positive with the future, very, very positive and I look after my health and I follow anything up they find and nearly everything's negative they find so, um, we'll keep it like that. I shall die of old age, well I've got old age now, you know what I mean (laughs), older age.

Summary of Roger's experience of long-term cancer survivorship

Roger's narrative is one of acceptance. He feels cancer is just one of those things that can happen. His ability to accept his diagnosis, and the consequences of treatment, particularly impaired sexual function, is mediated by his life stage, his sexuality, the fact that he has a strong faith and support from the church

community, and his supportive relationship with Ian. Good communication with healthcare professionals and his partner has helped Roger accept what has happened to him, and enabled him to integrate cancer into his life: *'...not having anyone to discuss it with, that must be the biggest problem I should think.'* The importance of communication is perhaps clear in his decision to volunteer for a cancer charity, giving small talks to groups of men and their partners. It is also clear in his call for gay support groups, so men can discuss treatment options, how to tell their partner, long-term effects of treatment, etc. – something he felt was lacking when he was diagnosed.

Richard's story

Richard (first interview): ...you do become a different person. As I said to you earlier, everything to me now is pre, during and post-cancer. Cancer is the overriding, sort of, focal point of everything I do.

Richard was in his early 50s when he was diagnosed with prostate cancer. At the time of his diagnosis, he was married, with children in their teens and early twenties. Richard was a successful businessman; able to retire early. He is a magistrate, and continued in this role throughout the cancer experience. Richard received hormone therapy, which he began soon after diagnosis. He also had radiotherapy and high-dose-rate (HDR) brachytherapy, but opted against surgery. At the time of our interviews, Richard was five years post-treatment, in his late 50s, and still married. He now lives with the late-effects of treatment, and an ongoing fear of recurrence.

Who is Richard today?

Prior to his diagnosis, Richard said he took everything for granted. He acknowledged that cancer *'does change your whole attitude to everything.'* He said *'you become*

far more appreciative of things, and far more tolerant of things when they go wrong. Cancer is now the *'focal point'* of Richard's life - his life is defined by cancer. However, despite experiencing the ongoing consequences of treatment, cancer has also had a positive effect on him. Underlying Richard's narrative is the importance of family. He has *'encapsulated'* his life, saying he focuses on the people he cares about, and activities he enjoys doing. As such, his life is *'more concentrated and happier'*. He feels he is a better person as a result of cancer: *'less selfish, more helpful'*. However, whilst *'drawing the horns in'* was voluntary, and in many ways positive, it does seem that his life has also been *'encapsulated'* involuntarily, in terms of the restricted life he now leads as a result of impaired physical functioning. Whilst cancer has imposed physical limitations on Richard, he said that as long as he can use his brain, and has a purpose, for example, doing his magistrate work, *'I'm reasonably content.'*

Richard feels it is *'payback time'*. He said a lot of time and money was spent treating him, so the least he can do is give his time and put something back into the *'cancer system'*. Richard campaigns for a more accurate screening test than the PSA test, and national screening programme, to ensure men are diagnosed early. His desire to give something back could be linked to feelings of survivor guilt. It seems Richard feels guilty that he was treated at a centre of excellence and received a relatively new, and expensive, treatment. He spoke to a man who was struggling to get brachytherapy. He was going to have to pay for the treatment, which Richard put down to the *'postcode lottery.'* Richard also talked about feeling guilty that he has survived, whilst others do not. When talking about a former colleague who died from prostate cancer, he questioned *'Why did he die and I didn't? You know, how am I so lucky and he's not?'*

Richard lives with a constant fear of recurrence:

EB (follow-up interview): ...To what extent do you worry it might come back?

Richard: Oh, all the time, I mean it's a constant thought in the back of your mind. What happens is, you get a, say for instance I had a really bad back pain recently, which is very near to where all the radiotherapy was and all the damage was and my first thought was, not that I've sprained my back, but that the cancer has got into my spine, which is rubbish, it hadn't, you know it was a back pain and it went away but that's the kind of thinking, perverse thinking that you get when you're constantly worried that it's going to pop up somewhere else...

EB: And is there anything you do, or can do, to manage those anxieties?

Richard: Well, I think you just try to put them to one side as much as you possibly can. I don't let it destroy my day, constantly thinking "oh my God, it's going to come back tomorrow". I don't think like that, I try to put it out of my mind, keep busy, do interesting things, whatever. But it's lurking, it's like anything really that's troubled you for a long time, hidden away in the back there, somewhere, it'll pop up every now and again.

Perception of the concept of 'cancer survivorship'

Richard identified with the term 'cancer survivor' but went on to say '*I've actually got cancer. I never say to anybody "I did have cancer" so survivorship is accurate because you're never free of the risk of having cancer come back... you are never free of the cancer.*' Therefore, it seems Richard is 'surviving' cancer - not just the consequences of treatment, but also the disease itself:

EB (follow-up interview): And I also got a sense when we talked about this term 'survivorship' that you might interpret it as never being free of cancer, so you're 'surviving', you didn't necessarily say that you had 'survived' cancer...

Richard: No, I don't think you can say that. I have, very happily, just been told that, with my latest test, I'm quite sure if I'd had that when we met or not? I'm clear now for the 5-year remission marker, which is just amazing, but it's only a theoretical marker. I know you probably hear about this quite a lot, 5 years is some kind of hurdle. Well it is a hurdle, but it's not the end. It's a theoretical hurdle. I know people who've been clear

for 5 years and then 2 years later died. So, you know, you're never free, you can't say "I am free of cancer" you can say "at the moment I'm free of cancer."

Richard also feels strongly that he is 'fighting' cancer and identifies with the 'battle' analogy:

Richard (follow-up interview): ...when somebody tells you there's this foreign body eating away inside you, your instinct is to get it out and throw it away. Not necessarily by surgery but somehow, you want to kill off this thing that's trying to kill you. That's a battle. It is trying to kill you and you're trying to kill it. If that's not a battle I don't know what is. So the first thing I did, when I realised I really was in trouble, was I got out a folder and with a huge, thick pen wrote 'war file' on it and then gradually as I gathered information, I filled up this war file with all that information. And then formulated my decision based on that. So you, it was bit like a general going to war.

Relationships, interaction and communication

Richard is a family-orientated man, who said he now has a greater appreciation for his family, and their lives together. He hopes he is a better father, and more understanding husband today. However, cancer is still affecting Richard's family five years post-treatment: *'cancer rules your life... it just takes over and it affects everybody around that person as well.'* He feels his wife and children worry about the ongoing problems he has, and also worry about whether cancer will come back.

Richard (first interview): ...but you don't tend to talk about it too much [as a family], it's an undercurrent. They didn't want to talk about it too much to distress me and I was too busy to ask them how they were feeling about it all because I was continually going back and forwards to hospital. It's a difficult time for a family...

Reiterating the importance of family that underscores Richard's narrative, his hopes for the future centre on him being alive to support his family, and see his daughter get married: *'...if you like, [I'm] the rock behind which they can all go off, live their*

life, but they can always come back to me if they get struck... so I kind of feel I'm the hub around which the family will evolve.'

Day-to-day living

Richard (first interview): I'm five years down the line, yes, I'm alive, my family haven't lost their husband and dad, but it's still having an impact on my life.

In terms of day-to-day living, Richard said *'physically, I have been forced to change.'* He described prostate cancer as *'very disruptive to be treated, with horrible side effects.'* Radiotherapy aggravated a pre-existing irregular heartbeat. Whilst preparing for an operation to rectify it, Richard took Warfarin, a blood-thinning agent. This opened his radiotherapy wounds and, as a result, he now develops blood clots, which can lead to extreme urine retention. The clots require self-catheterisation to clear, which in turn causes infections that need to be treated with antibiotics. He acknowledged that had he not agreed to the surgical procedure to treat his irregular heartbeat, he would not have the urological problems he does today. He said he has *'gone backwards and it's all down to radiation damage'*, as he had a couple of years post-treatment when life had effectively got *'back to normal.'* He finds the ongoing impact *'exhausting'* and *'annoying'*, but feels he is in control of his urological problems, wanting, and able, to manage them himself for the most part. However, these urological problems (as well as the heart defect) restrict Richard's daily activities. For example, he has mobility problems. He cannot walk far, and gets out of breath easily. As a result of the need to self-catheterise, Richard cannot be far from a clean, private toilet. This limits where he can go, so he stays at home more than he would normally. Richard said there are things he wants to do, but cannot, and there are days when he is too ill to do anything at all. He can no longer participate in some of the social activities and hobbies he enjoyed previously, including maintaining his garden.

Richard said that he is somewhat restricted in terms of overseas travel and mentioned that if he could stop using catheters, travel would be easier: *'there are complications with using those things and of course you have to calculate how many you need to take with you when you go abroad, cos you can't run out.'* Richard did say that if the clotting stops, and the infections go away, he will be able to get out more, and travel would be easier. However, he admitted that *'in terms of my lifestyle, I don't think I'd change very much to be honest. It would just be more enjoyable.'*

Summary of Richard's experience of long-term cancer survivorship

Richard's narrative highlighted positive changes to his sense of self and relationships, as well as his view of life. He also feels he is able to help others with prostate cancer through his involvement with a cancer charity. Richard has *'encapsulated'* his life – focusing on the people and activities he enjoys, which has brought happiness and contentment. These gains are mediated by the fact Richard feels cancer is *'insidious'* – it not only affects him, but his family as well. A loss of physical functioning and poorer health overall restricts Richard's life today. In addition, fear of recurrence means Richard lives with an uncertainty about the future. He is aware that his future could be affected by cancer again. Indeed, he can only say he is free of cancer *'at the moment'* and fears cancer *'will pop up somewhere, some time.'*

Margaret's story

Margaret (first interview): ...and I don't think now, I mean I just don't think about it
[corrects herself.] No, it's not something that's constantly in my mind at all.

Margaret was in her late 40s when she was diagnosed with breast cancer. At the time of her diagnosis, she was married, with no children. She was working full-time,

travelling internationally as part of her role. Margaret took five months off work for treatment: a lumpectomy, followed by radiotherapy. She then took Tamoxifen for five years. She attended follow-up appointments for an undetermined period, stopping when she forgot to attend on one occasion. However, she attends mammography screening today, and has taken part in the national bowel-screening programme. At the time of our interviews, Margaret was sixteen years post-treatment. She is in her mid-60s and still married. She is retired but continues to work on a consultancy basis. Margaret described cancer as the '*most major life event*' she has experienced.

Who is Margaret today?

A narrative of control underlies Margaret's account. This is in part historical, in terms of her upbringing (her family's '*Protestant ethic*' - show no weakness, serve others) and also her identity. Margaret came across as a fiercely independent woman. She was enjoying her career and was angry that cancer had come along when it did. She was determined breast cancer would not disrupt her busy working life.

When I asked Margaret how she would describe herself now, she said: '*the same, I don't see myself as any different really.*' She said her work formed an important part of her identity, and even though she has retired, she still does consultancy work. Margaret described herself as '*bossy, opinionated, stroppy*' but feels she is now more '*appreciative of other people's pressures*' and '*more sensitive to other people's situations.*'

However, whilst Margaret used to plan ahead, she now lives in the present. If she wants to do something, she will get on with it, rather than put it off.

EB (follow-up interview): How has the experience affected the way you currently view life?

Margaret: I suppose, it's almost like, I think, I don't know when, I used to live for what was going to happen 2 years down the line and was about planning things, I know that that has changed, it is about just living in the present and being present and just enjoying the day, you know, each day as it comes... And it made me think that, each day is, I don't know, I suppose you get your allotted time, I'm pretty stoical, is stoical the right word, I'm not sure, fairly, it's not complacent either, resigned? No, more of a, I suppose when my time comes, my time comes. I probably do more things now than wait. I think it's much more in the present, so if you want to go to things, if the opportunities come up, take them, rather than say 'I'm not sure about that'.

Perception of the concept of 'cancer survivorship'

Margaret perceives that she is 'living with cancer' as *'there might be cells in the body or something in my body has a propensity to, for the cells to change.'* Cancer could be lying *'dormant'*:

Margaret (first interview): ...You know, it's interesting people say they're living with cancer, I have to force myself to say that in a way. I'm easier about saying it now but for a while I would just say I've had it, I don't have it. And then I think well actually no Margaret, you're living with it. You know, the reality is you are living with it. It may be dormant but you're living with it.

EB: So you're living with the actual cancer rather than perhaps, I think sometimes people say they're living with the consequences of cancer, it sounds like you feel like you're living with it.

Margaret: No, I'm living with the potential of it coming back. It's like it happened once, it's not that I'm living, people talk about living with cancer once they've had it and it's been treated. I'm not living with the consequences of it.

Initially, Margaret said that, if asked, she would say she *'had'* cancer and that she is *'fine'* now. She does not feel she is going to die from cancer: *'In my head I'm going to die of something else, probably a stroke because that's what's in my family.'*

However, she contradicted herself in the follow-up interview saying that she is actually 'living with cancer':

Margaret (follow-up interview): I think from having sort of saying 'this is not something I'm going to die of' every now and then, you have to say 'no, it's not...' I used to say 'I had cancer', I used to hear other people, or in the literature saying 'living with cancer' and so I'm between 'I had cancer' and 'I'm living with cancer'.

EB: That was one of my questions I was going to ask you.

Margaret: I oscillate. I think, to persuade myself, I say 'I had cancer' but in reality I should be saying 'I'm living with cancer'. Because who knows whether it's going to come back.

However, the 'survivor' identity also resonates with Margaret because she has survived that specific episode of breast cancer: *'Yes, I am a survivor, and yes I can yes, but they're not, they don't trip off my tongue, it's not something, I'm a cancer survivor, you know. Don't wear it as a badge. But in conversation I'm happy to, yes, identify with that, yes, because I am literally yeah.'*

Margaret also talked about a '*sense of fighting*', linked to her desire to take control of her illness:

Margaret (first interview): ...I don't know if I visualised it as a fight. I think it was, it was more, yeah I suppose this isn't going to get me, but it was more, I think it was more positive. I don't know, sometimes fighting can be fighting against a, you know, you're here and you're trying to push it back. It's much more about I will take control of my life, I will look after myself, I will, it's about taking, it's not allowing it to control you, it's about taking control.

Relationships, interaction and communication

Margaret said she and her husband have become closer as a result of her diagnosis. Margaret did not talk at length about friends and family but did mention how she was seen as a *'success story'* amongst colleagues diagnosed with cancer. Margaret spoke more about how she was a source of support to others, rather than using other people with cancer a source of support herself. Other people with cancer remind her that she is well, but they also make her question for how much longer?

EB (first interview): And how about in terms of seeking help and support [from other women with breast cancer]?

Margaret: I suppose in a way I was not conscious of it, but thinking about it now I suppose in a way it just reaffirmed that I was better and that I was okay. You know, it wasn't that, or sometimes it made me think "oh shit is it going to come back?" You know, and it was probably also to be able to say "well I'm fine now" but I may not be, and one just has to deal with it. So in a way it was reaffirming that I was okay, but it also had that element of "so far", or it may come, you know, I don't know.

Day-to-day living

Cancer does not appear to affect Margaret's daily functioning. She said *'I've just got on and got on with life and gone to work.'* She went on to say that sometimes she has to remind herself she had cancer. She feels the extra time she spent recovering in hospital prevented her from developing lymphoedema. However, she does get sore around the site of her surgery after more strenuous activity such as gardening or walking briskly. In these situations, she said *'I'll just keep an eye on that'* and later said she only worries *'when you feel a pain and you think "oh shoot, is it my bra's too tight or is it something else?"'* One reminder, however, is that her breasts *'are all odd, now odd, yes, that's just a little sad but there you are.'* This was the only reference Margaret made to her body image. Margaret admitted that she is not

very good at being breast aware, but she does attend mammography screening. She said *'I know I should be but I don't, it just doesn't occur to me.'*

Margaret tries to eat healthily, takes exercise and looks after herself. I think this is partly due to concerns about ageing more generally, as well as trying to prevent cancer recurrence: *'although you might want to be like you're 18 or 21, the reality is you age, so you need to be doing things that ensure you remain mobile and flexible and things like that.'* She mentioned that she is more worried about bowel cancer, which might have influenced her diet.

Summary of Margaret's experience of long-term cancer survivorship

A desire to maintain control underpins Margaret's narrative, but it sits within the wider context of ageing and health. Margaret is aware that she must not be complacent about her health. She is more concerned about having a stroke or developing dementia (conditions that are more prevalent in her family) than a recurrence of breast cancer, but that does not mean she is not aware that breast cancer could come back. Indeed, she feels cells have the propensity to change in her body and that cancer could be lying *'dormant'*. As such, she acknowledged that she is actually *'living with cancer'*.

Patricia's story

Patricia (first interview): A little hiccup might describe my cancer perhaps.

Patricia was in her mid-50s when she was diagnosed with breast cancer. At the time of her diagnosis, she was married, with adult children. Arthritis forced her to retire shortly before her diagnosis. Patricia had a mastectomy, followed by radiotherapy and chemotherapy. She took Tamoxifen, and had follow-up appointments for five years. Patricia had to wait around eighteen months for reconstructive surgery,

wearing a prosthesis until that time. She had two unsuccessful reconstructions but a third operation was successful. At the time of our interviews, Patricia was eleven years post-treatment. She is in her mid-60s and divorced.

Who is Patricia today?

Patricia described cancer as a *'hiccup'*. She said other health conditions, as well as her marriage breakdown, have had more of an impact on her life. Cancer is one of several health conditions she has had to overcome. Indeed, as she and her friends get older, Patricia feels *'everybody's got something.'*

The period from diagnosis to when she had her third, and final, reconstruction (two years after she finished chemotherapy) was particularly difficult for Patricia. She felt that losing her breast and hair, and gaining weight, were more traumatic than being diagnosed with breast cancer. She was unable to have an immediate reconstruction, which she described as the point when her *'world ended'*. There were subsequent problems which resulted in three attempts at reconstructive surgery before she was able to establish what she referred to as a *'new me'*. Patricia said she was *'back to what I was. It's not real, but it's, it is real in another way'* after her breast reconstruction. Losing weight, hair re-growth and, in particular, being able to colour her hair, were further turning points, as Patricia regained her confidence and femininity:

Patricia (first interview): 'If you've lost a breast and you've got this prosthesis, every morning is a reminder. All right, I'll never forget I've had breast cancer, but [the reconstruction] looks so normal.'

Patricia (follow-up interview): I can't understand any woman not wanting to be, not perfect, but as a woman... you want to be as feminine as possible

Patricia feels cancer has changed her: *'I think you become a different person. I've hardened up I think, and with my marital issues as well. I won't say "yes" if I don't want to do something because I would run around after other people... I've not got as much tolerance now.'* She later reiterated that cancer has made her stronger: *'I was somebody people could trample all over.'* She said cancer *'makes you realise every day is special.'* She feels life is short and precious *'and I think that's what everybody who's had a life-threatening illness realises.'* She went on to say *'it does teach you really to not be complacent and get on with life. Do what you want to do.'* Patricia reiterated this in the follow-up interview, saying *'I grab at life now, and I would say to other people "take every opportunity."'* She went on to say: *'The way I look at life now is "what makes my life better for me?'"*

Patricia is still involved in cancer-related activities. She has always helped others, but now uses her experience of breast cancer to support other women, and to improve services. Her involvement also serves as a way of coping. She is given hope for the future through meeting other 'survivors'. Contact with other people diagnosed with cancer *'reassesses your confidence to sort of say "I've made it."'* This confidence seems to stem from two perspectives. The first is meeting people who are living long-term after cancer: *'I met people who were ten years down the line, it gave me confidence, as I now give other people confidence.'* The second is meeting people at the beginning of their cancer *'journey'* because it helps reiterate that she has survived.

Perception of the concept of 'cancer survivorship'

Patricia described herself as a *'survivor'* on several occasions in the interviews. She said: *'I'm a survivor and it won't come back. I just always feel positive.'* She did not identify with the term *'living with cancer.'*

Patricia (first interview): I would say I've survived cancer, because some people still, at the Macmillan conference two years ago a couple of them still felt even five years

down the line they were living with cancer, and there was a seminary about living with cancer, but I don't feel I'm living with cancer. I feel it's behind me now.

Patricia (follow-up interview): You know, I'm a survivor. I don't sort of think "oh gosh, it's going to come back". If it does, I got through it once and there's no reason why I wouldn't get through it again. But I think if it was going to come back it would have come back between the two and five years.

Relationships, interaction and communication

Problems Patricia was experiencing in her marriage were exacerbated by her cancer diagnosis. Fundamentally, Patricia felt her husband did not support her in the way she would have liked or hoped:

Patricia (first interview): ...he couldn't handle my talking about the cancer, people coming around to see me, and as one friend, she had a similar, her husband she was a lot older and it was his fourth marriage, and she said it's almost as though they're jealous of you because you're the centre of attention. You don't want to be ill, but he felt as though he was neglected. Well I wasn't neglecting him, but he just, the marriage just disintegrated...

However, she keeps in touch with her ex-husband and has recently seen a change in his understanding of her cancer experience, as a result of his own illness experience:

Patricia (follow-up interview): I mean now my husband's been ill, I think he's realised. I think that's maybe the turning point, he's sort of realising. Because he's been having the PSA test... But I do feel his illness in the past six months now has made him a sort of, a lot more understanding.

Patricia would like to be in a relationship as she feels lonely and wishes she had someone to share her life with. She feels this when she is going about her daily life, for example, when doing household chores and wishes someone was there to help

her: *'It's when you're on your own, there's nobody to empty the dishwasher.'* I did not get the impression that cancer has prevented Patricia from meeting a new partner. Indeed she spoke of a close male friend, with whom she would like to have a relationship. She has been open about cancer and her reconstructive surgery, and he responded by saying it is the person inside that is more important.

Day-to-day living

Cancer has very little impact on Patricia's life today. It seems managing other health conditions has moved the focus away from cancer in recent years. Knee problems impact on Patricia's mobility, and her ability to do certain activities. She can no longer swim or do gardening, both activities she enjoyed. Patricia mentioned that she still gets very tired, but acknowledged that was common for people who have had cancer. However, it does not seem to prevent her from maintaining her busy social life, as well as volunteer work and attending cancer meetings. She appears to live a very full life.

We did not talk explicitly about the future, but it is clear from her narrative that Patricia is more concerned about other health conditions than cancer recurrence. She worries about future mobility, and whether she will be able to carry out simple tasks, such as driving, and continue with social activities.

Patricia (first interview): ...It was the osteoporosis consultant who said you've got to lose the weight because of your knees. Then of course I've since had the right knee done twice, and I'm waiting to go to the pain clinic because they don't want to do it again or I could lose my leg... But that worried me more than the cancer because it's mobility now, that getting in and out of the car and going up and down stairs.

EB: And your quality of life.

Patricia: That's right. I can't swim and I can't, I've loved my garden. I had transformed gardens, and I had to have a flat because I just couldn't garden on my own and it's a shame.

Summary of Patricia's experience of long-term cancer survivorship

The legacy of cancer in Patricia's life is predominantly positive. She has an optimistic view of life and experienced positive changes to her sense of self. Her positive attitude also seems to mitigate concerns about recurrence, as she focuses on making the most of each day and opportunity. Even distressing events have resulted in positive action or experiences. For example, Patricia's marriage broke down but she moved to another part of England to start a new life for herself - one that is very active, and allows her to see more of her family. Equally, whilst Patricia experienced an assault on her body image and femininity, in her mind, the mastectomy removed the cancer, which helped reassure her that it would not come back. Equally, the reconstruction helped her feel *'back to what I was.'* As a result, she is now able to support others through her involvement with cancer charities. Meeting other women who have survived helps reassure Patricia that cancer is behind her.

Angela's story

Angela (first interview): I come back to the fact that I've actually gained, I've actually benefited from it. But then I've never had it as bad as, I'm sure there's a lot of people, I almost feel quite embarrassed saying it but if I'm honest with you, because my cancer, I suppose, wasn't life-threatening and I've had no reoccurrences, I think I've gained out of it. But I would hate for you, not that I need to tell you, for you to think that's the norm, and I'm almost embarrassed saying it, but I do think I gained from it.

Angela was in her mid-50s when she was diagnosed with breast cancer. At the time of her diagnosis, Angela was divorced, with adult children and working full-time.

Her mother was in hospital with breast cancer, and died around the time of Angela's diagnosis. She had a lumpectomy and lymph node clearance. However, she had to go back for a second operation to take a wider margin. She had radiotherapy, through which she continued working. Angela then took Arimidex for five years. She continues to have annual follow-up appointments and does not know how long these will continue for. At the time of our interviews, Angela was six years post-treatment. She is in her early 60s, living alone, retired from full-time employment but working part-time locally.

Who is Angela today?

Angela (first interview): I know this sounds a bit of a cliché and I would imagine that quite a few people say it, but it's definitely true. I am a different person since that year. I don't really, I think of what I went through, that whole year and there's been other stuff that goes on in life, and you think "my God". Other people see me as being quite strong, I see myself as being quite weak. However, when you get through all this, you just think, quietly you do feel quite proud of the way you've dealt with it, the way that you've let other people see that it hasn't got you. It's not something I say regularly but you are only as good as you get up in the morning so, you know, get out there. Get out there and do. And I definitely, I know a lot of people have done that and think like that. It's not about particularly, climbing mountains, it isn't about doing those sort of things really, just about making sure you don't waste time.

With hindsight, Angela feels that cancer is not the worst thing that has happened to her. She considers her divorce and her mother's death to be worse. Cancer and other life events were described as a '*little blips*' and '*little knocks, little fears.*' Angela also compared herself to others who she perceives have been through far worse – despite the fact that she has been through a protracted divorce, experienced other health problems and lost her mother to cancer around the time she was diagnosed herself. These examples demonstrate Angela positive approach to life.

Angela (first interview): I've got through quite a, not as, I mean some people have horrendous stories to tell, mine are just little blips along the way, which is life really, isn't it?

Angela's narrative demonstrates evidence of growth. She feels she has gained from the cancer experience – she is stronger and more confident today. However, she said she feels embarrassed to say she has benefited from the experience and did not want me, or others, to think this was the norm. Whilst people she knows consider her a strong person, probably because of the other life events she has been through, Angela said she has always thought of herself as *'weak'*. However, she feels proud of the way she coped with cancer. She did not let it get to her, and handled herself well, adopting a positive attitude throughout, which continues today. She feels she has *'earned'* strength and confidence over the years: *'I'm a hell of a lot stronger now.'*

Angela believes life is short. She adopts a philosophy of *'get out there and do'* - *'making sure you don't waste time.'* Her diagnosis was one of a series of events that encouraged her to reduce the amount of stress in her life. Post-diagnosis, she admitted that her work-life balance was wrong as her job was highly pressurised. She took six weeks off to travel for her 60th birthday. Whilst away, she reflected on her diagnosis, and her mother's death, and decided that she needed to reduce the amount of stress in her life and, to do so, she needed to retire. As such, Angela's diagnosis was a contributing factor in her decision to leave her job.

Perception of the concept of 'cancer survivorship'

Angela said that whilst she might be a survivor, she does not see herself as such and would not want people to think that she portrayed herself in that way. She compared herself to other people affected by cancer, referring to her diagnosis as *'relatively minor'* and that those with more serious cancers are survivors in her eyes. She also does not identify with the term *'living with cancer'* as she feels she *had*

cancer; it is over. However, Angela is aware that cancer can come back, but does not dwell on it. She adopts a matter-of-fact approach, effectively saying that she got through it once and would deal with it in the same way if it happens again. I think it helps that she feels she is being looked after by the NHS: *'...you're in this nice umbrella now whereby you're looked after. So, although I still keep an eye on myself, I just know, you know, if it is caught or if something happens again, I'm there aren't I?'*

EB (first interview): And what has been particularly helpful in terms of helping you get through your experience of cancer?

Angela: I'm not sure really. I think I've, actually, you have to understand I am definitely a positive person anyway, I'm not negative, I do not think this is going to come back next week or next year. I now know that even if it did, the chances are it would be another operation, another bit of treatment, it might even be a breast op, but I don't see that, if that happens, that happens. It's not something that scares the life out of me anymore, I'm not scared.

Relationships, interaction and communication

Angela is close to her children, but this seems to have always been the case. Cancer has reinforced Angela's identity as a grandparent. She wants to pass on her values to her grandchildren, and for them to see her as a role model – someone who is strong and independent, remains active and healthy and embraces life. Angela feels her family need her more than she needs them and that they are still concerned, even though, to her, cancer is in the past. Angela does not want them worry about her now, as they have their own lives and children to take care of. Interestingly, she said *'you want them not to be worrying about me at this time, it's bad enough when I get a lot older'* suggesting that she aware her children might have to care for her in the future. This may stem from the fact that she had to care for her own mother when she was ill.

It appears Angela feels she has to behave in a way that is socially acceptable to others. She does not talk to people she does not know well about cancer, as she perceives it as something people do not talk about. Angela said she needs to be seen to be coping. It seems, at times, she puts on a façade for her friends and family, in part to protect them, but also to maintain, in their eyes, a sense of the person she wants them to think she is. She mentioned that a couple of friends see her as an *'inspiration'* in terms of her positive attitude towards cancer, and life more generally, and she might want to maintain that ideal in their minds. She said her friends would not want to see her *'wallowing'* about how cancer could come back.

Day-to-day living

Six years post-treatment, Angela is starting to experience bone-thinning, which could be a late effect of radiotherapy and Arimidex, or due to ageing more generally. As a result, she experiences backache when she does more strenuous activities. Angela found the results of the bone density scan *'depressing'* because she worries it may restrict her active lifestyle in the future - she is not one to sit around and do nothing. She also said bone-thinning makes her *'a little bit nervous'* because it serves as a reminder that she had cancer. However, Angela is making a conscious effort to maintain her healthy lifestyle. She eats healthily, trying to consume foods high in calcium, is sourcing a Pilates class and tries to jog, if her back will let her.

Summary of Angela's experience of long-term cancer survivorship

For Angela, cancer was a *'little blip'*. It was not the worst thing that has happened to her – going through a divorce and losing her mother were more difficult in her eyes. She has approached cancer with a positive attitude and said she has gained from the experience, both in terms of her identity and outlook on life. Angela is a

different person - stronger and more confident - as a result of the cancer experience. She is not scared that cancer will come back. However, this is not to say she is not aware it could. Angela is more concerned about the impact ageing, and the potential problems associated with bone-thinning, might have on her ability to maintain her active lifestyle. Despite this, Angela is an example of someone who has experienced post-traumatic growth as a result of her cancer experience.

Moira's story

Moira (first interview) ...mentally, I think it, that's a very difficult one because that comes and goes, I think. I think some people may be absolutely devastated all the way through and straight off. I wasn't. It sort of came and went. I had a lot of sort of positive feelings about it and then some huge troughs really and I mean I think that kind of continues because you live with the thought that you were a cancer patient forever more really and I think, day to day you forget but it lives with you.

Moira was in her mid-40s when she was diagnosed with breast cancer, after a Well-woman check-up. At the time of her diagnosis, Moira was married, with young children. She had a mastectomy, followed by chemotherapy. Moira did not have a reconstruction, and it was not discussed at the time of her surgery. At the time of our interviews, Moira was sixteen years post-treatment. She has not had a reconstruction but wears a prosthesis. Moira continues to have annual follow-up appointments with a private breast surgeon. She volunteers for breast cancer charities and has taken part in various fundraising events. She is in her mid-60s, still married, and her children are grown up.

Who is Moira today?

Moira described '*a loss of confidence that lives with you*' after a cancer diagnosis. She outlined different '*levels*' of loss, firstly relating to a loss of confidence about health, and secondly, a loss of confidence in her body image. The loss of confidence

about health is a legacy that continues to make Moira nervous. As a result, she is aware of her own mortality, and although her diagnosis was some time ago, she has found herself saying *'the cancer could come back, or a different cancer could come back'*. The uncertainty she feels regarding her health is not constant, and tends to occur when she is ill or tired, linked, she said, to the fact that she did not have any symptoms, apart from tiredness, when she was diagnosed.

Moira talked about the clinical perception of cancer recurrence when the cancer survivor is many years post-treatment. To her, if she were diagnosed again, it would be related to her original diagnosis. However, she suggested healthcare professionals would say it was not related to the original diagnosis:

Moira (follow-up interview): I don't know whether this is medically correct but I think what tends to happen now is, if you have survived for sort of 15/20 years, and then a cancer does come back, they tend to treat it, medically, as a new cancer, not a recurrence, and I think, I'm not sure how I feel about that. I mean, deep down inside, I'm not sure how I feel about that because I think if it did come back, if I do get cancer again, I would feel "well I've got it again" and I would think it was linked. I'd find it very difficult to think "well that was my life then, and I had cancer then. Now I have it and it's a completely different thing." I think I would think "well, here we go again" sort of thing.

Cancer does not keep Moira *'awake at night'*, nor does she *'look for cancer around every corner.'* She is philosophical about the future, saying, *'I'm in my 60s now so, you know, I could carry on for another 30 years or something could happen to me, I don't know. But it's not something that I dwell on...'*

Moira feels she is the same strong person she was before her diagnosis. Penny said *'...she's back to as she was before, still strong, still positive but perhaps a little more realistic.'* However, Moira continues to be affected by the loss of her breast. She described the loss of confidence in her body image as *'quite frivolous, it's, you know, how you look really'*. However, it clearly affects her, particularly in the

summer, when her normally private self is exposed publically, for example, when wearing a swimming costume. In the winter, she said everyone is covered up, implying that the loss of a breast is not publicly visible. Privately, Moira said the loss of a breast is not an issue as she comes from an open family where she feels comfortable in front them.

Moira (follow-up interview): I haven't had a reconstruction and weeks go past and I don't even think about it but then something will happen in my life where I've got to be on a beach with other people in a swimming costume or I want to go out in a proper evening dress where I can't wear a jacket or something, and yes, I think that affects me slightly as well.

It is during the summer that the question of whether or not to have a reconstruction is raised. However, Moira said she has not had a reconstruction as she does not want to '*upset the balance*' of her life, as she is now in her 60s and it would be a major operation.

Perception of the concept of 'cancer survivorship'

Moira (follow-up interview): I think [cancer] hasn't got a great part in my life but, there is a part of me that will always be a cancer patient I think, and I think that is something I can't really get away from. Yeah, I don't know whether other people can literally just put it behind them and forget about it completely, but I don't think I can totally.

Day-to-day, Moira said she can forget that she had cancer, but '*you live with thought that you were a cancer patient forever more really.*' If someone asked her about her diagnosis, she would say '*it's a long time ago now and I've been well since.*' However, she described herself, and other women diagnosed with breast cancer, on a couple of occasions, as '*sufferers*'. Moira said cancer is '*something that's attached to you. I mean, you can be whatever you are, but you're also a cancer patient or a cancer survivor or whatever and I think that stays with you.*' She

went on to say that, day-to-day, she does not identify with being a *'cancer survivor'* but occasionally she might say she is one.

Relationships, interaction and communication

Moira's existing relationships do not appear to have been affected by her cancer experience. However, she has developed new relationships with other women diagnosed with breast cancer, through her volunteer work. She feels a *'connection'* with these women, and a need to share experiences. Giving and receiving peer support is still important today:

Moira (follow-up interview): ...it's always a comfort, I think even a long way down the road to find that people will say "oh gosh I've got to go for my mammogram next week and it always makes me terribly nervous and I don't sleep". I think you feel that, you know, you're not alone in that..

Moira sees volunteering as *'hugely positive'* in two respects. Firstly, as a result of the people she has met and the peer support she has gained and, secondly, through the interesting events she has been involved in. Moira feels her involvement with cancer charities has in no way been a negative experience: *'you get pulled into that world and you find that it's not such a bad world. It really isn't. I mean there's an awful lot of good things that happened to me...'* As Moira said, *'you've had your turn at being ill, and then you're better, and you can give something back.'*

Day-to-day living

Cancer does not affect Moira's daily functioning. However, she mentioned some side effects of chemotherapy, including a tingling sensation in her fingers. She is also more prone to stomach upsets. As already discussed, cancer has left a legacy in terms of a lack of confidence about health, particularly when Moira is ill or tired for

no explicable reason. At these times, feelings of uncertainty about recurrence come to the foreground.

Summary of Moira's experience of long-term cancer survivorship

Moira's narrative speaks of gains and losses as a result of the cancer experience. Whilst she sometimes struggles with the loss of her breast, and a loss of confidence about her health, she described herself as *'well'* and continues to give back, supporting other women diagnosed with breast cancer through her involvement with cancer charities. Through volunteering, she experiences a *'connection'* with other women, which is a source of support and comfort to her. Being *'pulled'* into the cancer *'world'*, she realised it is not such a bad place and *'an awful lot of good things'* have happened to her as a result.

Malcolm's story

Malcolm (first interview): ...I don't consider I still have cancer. I have the effects, which I have to live with, having had cancer, and more importantly, cancer treatment.

Malcolm was in his late 50s when he was diagnosed with colorectal cancer. At the time of his diagnosis, he was married, had adult children and was working in higher education. He had surgery (a resection and temporary ileostomy) followed by chemotherapy. He delayed presenting symptoms to his GP so he wonders, had he seen his GP sooner, whether he would have needed chemotherapy. The ileostomy was reversed approximately a year after surgery. Two years after that, he had surgery to repair a parastomal hernia and incisional hernia. At the time of our interview, Malcolm was almost seven years post-treatment. He is still married, but was forced to retire from his academic role as a result of *'chemo-brain'*. However, he continues to work on an ad-hoc basis in the education sector. He also volunteers for a cancer charity, reviewing literature and contributing to research activities. Just

before Malcolm reached the five-year marker, he and his wife moved to another part of England. However, this meant he was separated from his GP, who had been an important source of advice and support throughout his cancer experience.

Who is Malcolm today?

Malcolm (first interview): I'm one of these strange people who really, in a sense, it's there, it's happened and it hasn't really affected me in that respect. I don't think I'm any more immortal or mortal than I was before.

Malcolm said that cancer has not changed him as a person, nor has it affected his outlook on life. It seems cancer was an illness that was treated and is now gone. When I asked him directly whether his life perspective had changed in any way, he asked '*in what way?*' Examples I gave included changing priorities or a greater appreciation for, or changed outlook on, life. His response was: '*well, we were doing all those things anyway. We did retire, technically.*' So, it seems that retiring may have been a bigger life change for Malcolm and his wife than cancer.

The five-year marker was a key moment for Malcolm. He said healthcare professionals did not emphasise the marker, and no one said he was cured or in remission. Malcolm described the time as a '*bereavement*' – he was '*cut off*' from hospital support, and had moved away from a supportive GP. He was left wondering where he could turn to for advice *if* he needed it. It is as if the safety net of the hospital and his GP was taken away at that five-year point. He might not have used their services but it appears he was reassured by the fact they were there if he needed them.

Perception of the concept of 'cancer survivorship'

Malcolm said he *had* cancer. He does not see cancer as an issue now, particularly as he is past the five-year point. However, he does not identify with being a 'cancer

survivor'. He also does not agree with the phrase 'living with cancer' because as far as he is concerned, he does not have cancer anymore - he is '*living with the effects of cancer treatment.*' He suggested that, if anything, he was '*living after cancer*', but '*that's a stupid tautology of terms as well.*' Ultimately, he feels it will never be possible to find the right terminology. Interestingly, whilst Malcolm does not identify with the term 'cancer survivor', he mentioned that his wife, Barbara, had been diagnosed with cancer 20 years ago '*so she is a survivor*' – perhaps suggesting that he feels time since diagnosis is an indicator of when someone can be labelled a 'survivor'.

Relationships, interaction and communication

Malcolm did not talk at length about his relationships, but mentioned that one of the consequences of treatment is impotence. It was clear in the interview that he did not want to talk about it, and the impact it has on his relationship with his wife. Indeed, he said the way he manages it is by ignoring it. He said it does not often cause a problem, but occasionally it can be '*annoying*' and '*has an impact on family life.*' When I asked Malcolm whether his relationship with Barbara had changed as a result, he said: '*She just gets annoyed occasionally. But then, that's normal.*'

He also mentioned that some of his friends and colleagues have got what he referred to as '*cancer fatigue*' – that there is only so long they want to hear about cancer and its subsequent issues.

Day-to-day living

Malcolm said he is living with the consequences of cancer treatment. He mentioned chemotherapy in particular, but it was also clear in his narrative that long-term effects of pelvic surgery also impact his life. Malcolm mentioned chemo-brain, peripheral neuropathy, irregular bowel movements and impotence. He suggested

ways he manages each of these, but said they do not normally interfere with his daily life, just from time-to-time. Malcolm implied that these consequences can sometimes be an *'annoyance'* rather than a *'problem'*.

Malcolm (first interview): There's the ongoing problem of infrequent bowel pattern that has to be controlled... You have to know what foods to eat and not to eat. And then you make conscious choices if you want to eat something that you know you don't have... five or six frequent trips off to the toilet. That's fine as long as you're not entertaining. And so these sort of things have to be taken into account from that. In terms of the chemo-brain effect, you learn to live with and you know, you get to the stage where, if I'm doing a training session for instance, I'll just say "it's chemo-brain, just hold on a minute, I'll come back to you in second" kind of thing. So you sort of deal with that one. There is still sort of an ongoing, very occasional problem with some peripheral neuropathy, and that is more difficult to deal with as you never know when it's going to strike.

Malcolm also mentioned the impact of surgery on his ability to travel:

Malcolm (first interview): I mean a classic example actually, I still do a lot of travelling and whilst I'll quite happily travel in the back of an aeroplane for a short or medium haul flight, I will not travel in the back of an aeroplane for a long haul flight. The possibility of having to share one or two toilets with 200 other passengers... So, things which you don't think about as perhaps consequences of living with cancer are actually consequences.

Whilst Malcolm is living with the consequences of treatment, he feels other health conditions, in particular, diabetes, have the potential to have a greater impact on his future health. He said the risk of complications as a result of diabetes, such as a stroke or heart attack, are greater than any impact of cancer: *'I don't think [cancer] has any impact at all. As I say, the fact that I'm also a Type II diabetic has more potential impact than diagnosis and treatment of cancer.'*

Summary of Malcolm's experience of long-term cancer survivorship

Cancer has not impacted Malcolm's sense of self or relationships to any great extent, nor has it changed his perspective on life. Cancer was just an illness that he was treated for. However, Malcolm now experiences the ongoing side effects of treatment, which are an occasional '*annoyance*' but not a '*problem*' that interferes with his daily life. For example, when talking about trouble with his bowels, he said: '*it's there, it's happened, so what?*' Cancer charity involvement gives Malcolm a sense of satisfaction, as he is not only supporting an organisation that supported him through his cancer experience, but he can also keep his brain active, reviewing information. Moving away from a supportive GP, Malcolm felt '*cut off*' from his support system. Therefore, indirectly, receiving information from a cancer charity might be a reassuring source of support for Malcolm, at a time when he does not feel he has established as supportive and personal a relationship with his new GP.

Janet's story

Janet (follow-up interview): ...nobody has said "you got bowel cancer because of..." you know it was a poor diet or you didn't do this or it came through the family or whatever, they were not able to pinpoint why I got it, so consequently, you can't do anything to avoid getting it again if you see what I mean. You can't, I take measures as much as I can, as I said, good diet and all the rest of it, keeping active, been swimming today actually. But, if you don't know, I mean it's like smoking, if you know smoking's bad for you, you can give up. But if you don't know what's caused something, it's very difficult to do positive steps and feel that you've done something to actually prevent it coming back. So, that's why I just have this niggle, yeah it's been here once, what's to stop it coming back? But I do believe that the reason they check you for this length of time is that if you go the full 10 years with no hint of it coming back, they are confident that it is gone. So, I hope so anyway... I think it does make you look at your overall lifestyle, and think "what should I be doing, is there anything I'm not quite good enough at?"

Janet was in her early 50s when she was diagnosed with colorectal cancer. She had recently married her second husband, himself a cancer survivor. Janet has an adult daughter from her marriage to her first husband, who died from cancer. Janet was working full-time when she was diagnosed. She had surgery (a resection which did not require a colostomy bag), followed by chemotherapy. At the time of our interviews, Janet was almost six years post-treatment. She had just turned 60. Janet took early retirement after her cancer treatment and now likes to spend time gardening and with her family. She volunteers for a cancer charity, reviewing literature, contributing to research activities and fundraising.

Who is Janet today?

Janet said that, each year that passes gives her the confidence to say she has survived colorectal cancer and can look past that particular cancer episode to the future. Ongoing follow-up tests serve not as means of checking whether cancer has returned, but reassure her it is still gone. Janet's last follow-up colonoscopy is scheduled for 2014, ten years post-diagnosis, and she said that is something to look forward to. This being said, Janet feels she is '*prone*' to cancer. Indeed, she said that when she dies, it will be as a result of some form of cancer. There seem to be several possible reasons for this. Janet had a hysterectomy after pre-cancerous cells were found during a routine smear test and her mother and grandmother had cancer. As a result, Janet took part in a study exploring family history of the disease. She was informed that her colorectal cancer was not hereditary. However, as Janet still does not know what caused her cancer, she has a '*niggling fear*' it might come back, and is frustrated she cannot do anything to prevent it.

Janet (first interview): I do feel that, for some reason I'm prone to it. Because of that. That's twice. If I get something else, I think I'll have a bit of a job fighting it, but nevertheless I will fight it.

Despite this, Janet said she worries more about what she might miss, rather than the possibility of recurrence itself: *'That's what worries me more than anything. The fact that I might not be around to see those things.'* For example, she mentioned that she wants to see her daughter get married and have children of her own.

Cancer, alongside taking early retirement, have had a positive effect on Janet, in that she is now living a life where she participates in the activities she loves, and enjoys close relationships with her immediate family. Taking early retirement allowed Janet to take a step back and reflect on everything that has happened to her in the recent past, including the death of her first husband, the subsequent impact this had on her lifestyle, deaths and illness in the family and her own diagnosis.

Despite feeling *'prone'* to cancer, Janet does not let this stop her from doing the things she enjoys. She sees other people *'fighting'* cancer and that gives her a *'boost'* and keeps her feeling positive. Indeed, between the interviews she adopted two cats, which demonstrates that she is looking to the future, as she feels confident she will be alive to look after them. Janet is more placid than she used to be, and tries not to let things upset her. She is also more tolerant and *'a little bit more laid back'*. She said she will not do things she does not want to, instead focusing on things she enjoys, such as her allotment.

EB (follow-up interview): I was just wondering if there was anything else that was particularly useful for you, to help you manage the experience?

Janet: Um, not really to be honest. I try to be positive in outlook. Hence getting new cats... So, I mean when you take on an animal, obviously, a cat or a dog, you've got to think, it could possibly live for 10, 12, 14 years, you know, so I'm being positive in that respect. Looking past the cancer and I think I did that when I was ill.

Perception of the concept of 'cancer survivorship'

Janet said she '*most definitely*' identifies with the term 'cancer survivor'. She feels 'cancer survivor' is a positive term, which conveys cancer is not simply a '*death warrant*' and that there is life afterwards. However, she does not endorse the term 'living with cancer' as she feels it relates to diagnosis and treatment, and she has passed that stage:

EB (follow-up interview): And another term that's used is 'living with cancer' and I wondered what you thought of that term, what it means to you?

Janet: I tend to take that very literally. I don't feel that I'm living with cancer. I've gone through that as far as I'm concerned. I have lived with it, and I made the most of it and I have come through the other side. So as far as I'm concerned, I'm no longer living with it. To me, living with cancer means that you are actually undergoing either treatment or diagnosis or whatever. I feel that I am passed that.

Relationships, interaction and communication

Janet said she is possibly '*a little more selfish*' with respect to people outside her immediate family. Her focus is on those close to her so she is '*more firm about what I will take on*' outside the family. Janet and Lucy have always been close. They were brought closer by the death of Janet's first husband, with Janet stating that looking after her daughter was what '*kept her sane*' after his death. However, they are now even closer, as Lucy has been a huge support during Janet's cancer experience. Over the years, Janet said '*we've sort of kept each other going.*' She said: '*I think it has definitely brought us together more.*' She also mentioned that there is '*a bit more tolerance on both sides I think.*' Janet acknowledged that now she has retired, and is not doing everything at '*full-speed*', she has the time to listen to her daughter. Equally, now her daughter is older and has moved away from home their relationship has improved.

Janet did not talk at length about her relationship with her second husband, Simon, other than to say that he is a *'huge support'*, and has a greater understanding because he is a *'cancer survivor'* himself: *'I do think that having gone through it himself, helped him to get me through it.'* Janet feels that him being a fourteen-year cancer survivor is a positive for her as it makes her feel *'he can do it, anybody can'*. She also said *'it's nice to know that we have an opportunity to keep going on together.'*

Day-to-day living

Janet said that one of the side effects of chemotherapy is chemo-brain which *'hits your memory something rotten... it's ridiculous words that you forget.'* She tries to keep her brain active by doing crosswords, and overcomes the memory loss by keeping pens and pads all over the house so she can make lists. However, she admitted that it *'annoys me to distraction... I do make a joke out of it, but I do regret losing my memory as much as I have done.'*

Janet described a daily habit of checking for blood every time she goes to the toilet, as this was a symptom of her cancer. Janet also has to watch what she eats to a certain extent. For example, curries have to be mild as highly spiced foods *'upset my bowels and do, I find I'm trotting...'* Although Janet watches what she eats, she said it is just something that is at the back of her mind: *'you know, I don't have to, when I go shopping, I don't have to think "oh I hadn't better buy that" you know? It's sort of so normal now.'* Janet also mentioned that since her operation, she has been good at eating her five-a-day, *'which tends to be about seven for me now. I eat lots, I try to eat as much fresh fruit and salad-y stuff... and try to eat stuff uncooked if I can, so it has made me much more aware of what I eat.'* This could be linked to the reading she has done around the link between poor diet and colorectal cancer. Whilst she does not feel she had a poor diet when she was diagnosed, it is possible that managing her diet is a way of taking some control over her risk of recurrence.

Overall, cancer has made Janet look at her lifestyle and question, “*what should I be doing? Is there anything I’m not quite good enough at?*” She looks after herself ‘*pretty well*’ and described her health status as ‘*good*.’

Janet (first interview): It’s at the back of your mind the whole time. It sounds, you’ll excuse me if this sounds crude, whenever I go to the toilet, I have to check. I always look. I have to make sure... and so that’s a daily habit... It could come back. And I think that’s just a niggling little fear that, unless you’re the sort of person who can overcome that, it’s always going to be there.

Summary of Janet’s experience of long-term cancer survivorship

The main legacy of cancer for Janet is a ‘*niggling little fear*’ that cancer could come back. She feels that when she passes, it will be as a result of some form of cancer. Whilst her episode of colorectal cancer is now almost seven years ago, she feels she could experience a recurrence as she is ‘*prone*’ to cancer. To manage this, she has adopted a healthy lifestyle, and takes part in various screening activities. This being said, she said the risk of recurrence does not worry her as much as thinking about what she would miss out on if she died. Despite this legacy, Janet does appear to have gained from the cancer experience. She has a closer relationship with her daughter and an altered sense of self and philosophy of life. Her cancer experience, alongside taking early retirement, means Janet tries to participate in activities she finds enjoyable.

Janet (follow-up interview): I think, um, I see it, in a way, it was almost a wasted year. You know, in that everything had to go on hold while I was having the chemotherapy and whatever. But in a way it was almost a positive waste. In some ways it was a waste because a year went, but on the other hand, it’s given me the rest of my life. And it has given me some of these positives. Sort of going forward from that, I think each year that I go past it, I feel more confident that I will keep going.

Andy's story³³

Andy (first interview): ...But I do think it will rear its head eventually. One day I'll wake up and that will be, you know. I reckon it will come back. Well you either die of a heart attack or cancer don't you? So, I reckon it will come back.

Andy was diagnosed with testicular cancer when he was in his late 20s. At the time of his diagnosis, he was in a serious relationship with Rachel. He had surgery to remove the affected testicle, and had a prosthetic testicle inserted. Post-surgery, he was told by healthcare professionals that he was 'cured'. However, he became depressed after treatment and engaged in self-destructive behaviour, including drinking heavily. He attended follow-up appointments for five years, which he found unsettling. However, he found discharge from follow-up an uncertain time as his 'security blanket' was taken away. At the time of interview, Andy was in his early 40s and fifteen years post-treatment. Married to Rachel, they have young children.

Who is Andy today?

Andy suggested that cancer might change you for a 'little bit', but then you get 'back to normal' because 'you are who you are.' He made reference to his mother, who also had cancer, saying that 'it did change my mum, didn't it? But she's sort of gone back to how she was. You should say things. If you feel you need to say things, she would say it, but she doesn't now.' Therefore, it seems Andy feels people make changes soon after diagnosis, but these changes do not last. However, Rachel feels that learning to deal with the cancer diagnosis, and more importantly, the legacy of cancer (particularly the fear associated with recurrence) has made Andy a stronger person. He said he is more positive in his outlook on life; living for today.

³³ In contrast to the other 12 participants, Andy's interview was conducted with his wife, Rachel. As it was a joint interview, their story is presented as an embedded case study (Yin, 2003).

Andy (first interview): I think now you've really got to live for today I reckon. You know, if you want something or whatever, have it. That's how I look at things now. If I want something I'll have it now. I won't wait for tomorrow. Will I?

Rachel: No.

Andy: I think that's the way you've got to live. So yeah it has changed my life like that. I don't live for tomorrow, no way. I live for today.

However, cancer has also compounded Andy's fear of death and he has a bleaker view of the future. He believes he will develop cancer again and it will be his cause of death.

Perception of the concept of 'cancer survivorship'

Andy (first interview): I don't think it ever goes away for anybody... You just have to, you learn to deal with it I think, eventually. And you've got to think, "oh God I can't keep thinking about it" cos we're all going to die I suppose.

Rachel said that when Andy was discharged from follow-up, he had to *'live with the fact that you are an ex-sufferer.'* Both agreed it was the five-year point that signalled the start of his survival. Rachel suggested Andy was a survivor after five years, and that it took him that long to feel that way. However, I wonder whether Andy thinks of himself as a 'survivor'. It seems he is 'living with cancer' as he used words like *'brewing'* and *'floating'* to describe cancer as something living within him. He also mentioned that *'now [health professionals] are not going to see me, something could be brewing up inside. The longer it goes on, I mean I wouldn't want to go for a full medical now, because you think "oh shit they might find something."*

Andy (first interview): ...a little pin head floating around in your body all the time and then it just stops somewhere and it might sit there for a little while and the, that's how it gets you I reckon.'

Relationships, interaction and communication

Andy and Rachel acknowledged that they have always had a *'volatile'* relationship, but they are still together and Rachel thinks they are stronger today as a result of overcoming the difficulties associated with Andy's cancer diagnosis, and subsequent destructive behaviour. Rachel said: *'I think it's made us stronger now, but going through it at the time was very difficult.'* Cancer does not affect Andy's sexual functioning today. His libido and fertility were not affected, as they went on to have children, the first towards the end of the transition phase of survivorship.

One issue Andy and Rachel raised was that Andy's prosthetic testicle does not have the same reactions as his other testicle, and hangs differently. It seems the prosthetic testicle was more of an issue closer to treatment, as Rachel said *'you obviously had a complex at that time'* to which Andy replied *'but it's pretty obvious isn't it?'* However, Andy said he was *'not bothered'* about losing a testicle, going on to say *'it obviously didn't make any difference as we've had kids'*. I asked him if he ever worried about his virility. He replied, that, closer to diagnosis it worried him *'massively. That was a real problem. But it's never affected me... I mean it was painful, so that would stop you [having sex] at times...but, in that respect, it still worked and as long as it worked, that was good enough for me.'* He said he would not have been happy to lose both testicles. Keeping one testicle, and having children, has enabled Andy to retain his masculine identity.

It was clear that Andy does not feel Rachel fully understands what he has been through because she has not had cancer herself:

Rachel: ...And living with someone who is going through that is difficult, cos you've still got your own life to lead as well, you're also trying to look after the person, who you know is ok, but they don't know they're ok.

Andy: But you say that, put yourself in their shoes.

Rachel: Absolutely. Yeah, but I'm talking from a spouse's point of view.

Rachel: You always said that to me. "You don't know what it's like"

Andy: Well you don't until...

Rachel: No I don't, again, that's how you felt isn't it?

Andy: And I thought it wasn't fair. I was quite angry about it to be honest, cos I felt alright and I thought "this has really pissed me off". Yeah so I got quite angry about it, but it would, well, I think it would make most people angry. Especially if, I was only about 28. I thought this can't be right, surely?

Day-to-day living

Cancer does not impact Andy's daily life, and his ability to carry out activities. However, he mentioned that he worries if he becomes ill: *'Even now, if I think, if there's something wrong with me, I think "I've got it." Even now.'* Andy recently had an ear infection and one of his glands was swollen: *'and I thought "oh that's one of them things in your neck." What is it? Lymph nodes. Cos they used to check all round there and that, and if I find a lump, that's it.'* This seems to be a historical concern from his follow-up appointments, which were a source of anxiety.

Andy is a deviant case in the sense that he followed a self-destructive path post-treatment, which is in contrast to the other narratives in this study. He was depressed and drank heavily. He thought that if he was going to die, he may as well die happy, so he would go out on *'benders'*. However, within the past couple of years, he has stopped drinking and takes a healthier, more positive approach to life. This was perhaps triggered by an event external to his cancer experience³⁴, rather

³⁴ Not shared here to maintain confidentiality

than cancer per se. Therefore, it may have taken an event unconnected to cancer to stop the destructive behaviour that worsened after his diagnosis.

Summary of Andy's experience of long-term cancer survivorship

Fifteen years post-treatment, cancer has left its legacy on Andy's life. Testicular cancer does not affect Andy's daily functioning. However, he feels he will develop cancer again, and that it will probably be the cause of his death. This is due to Andy's perception that no one in his family dies from anything else and that cancer cells are potentially '*brewing*' within him, '*floating*' around looking for somewhere to settle and grow. Over time, Andy has learnt to live with these feelings but when he is ill, he worries about recurrence, which exacerbates his fear of death and dying. As such, uncertainty and anxiety about the future underpin his narrative.

Summary and next steps

This chapter has presented a series of case studies to give the reader an insight into experiences of long-term survivorship across a range of cancer-types. I have described how cancer has affected participants' sense of self and outlook on life, the impact of cancer on daily living and relationships and how participants perceive the concept of 'survivorship' and being a 'cancer survivor'. As these 'restoried' accounts have demonstrated, there are similarities and differences across the stories told. These will be explored further in the cross-case analysis presented in Chapter 9. The next chapter presents a thematic analysis of the 'significant other' interviews, exploring their perceptions of who the person diagnosed with cancer is today and what impact, if any, they feel cancer has had on their loved one's sense of self and relationships with those close to them.

Chapter 8. Thematic analysis of ‘significant other’ accounts of long-term cancer survivorship

Introduction

As mentioned in the Methods chapter (Chapter 5), I had envisaged conducting separate interviews with individuals living long-term after a cancer diagnosis and their ‘significant others’ and then analysing the stories dyadically, exploring consensus and contradiction in the accounts presented. However, this posed a series of ethical dilemmas, particularly regarding anonymity and confidentiality. As a result, I decided to conduct a separate thematic analysis of the ‘significant other’ data collected through seven individual interviews and one joint interview. I was particularly interested in exploring ‘significant others’ perceptions of who the person diagnosed with cancer is today and what impact, if any, they feel cancer has had on their loved one’s sense of self and relationships with those close to them. Key themes that emerged from the ‘significant other’ accounts, which will be discussed in this chapter include: perception of the cause of cancer; physical functioning and health; how ‘significant others’ perceive the person diagnosed with cancer today; impact of cancer on relationships and communication; and the future.

Perception of the cause of cancer

Some ‘significant others’ touched on whether they felt the person diagnosed with cancer had thought about the cause of their disease. Responses varied, with some suggesting that the person diagnosed had questioned why they had been diagnosed. For example, Sheila mentioned that, today, when her husband is feeling low, he questions ‘why me?’: *‘That is often a thing that will come out if he’s very low. You know, “what have I done to deserve this?”’* Others felt their loved ones had accepted the diagnosis, either because cancer was perceived as a common

disease or just something that happened to people, but had not established a reason as to why they had been diagnosed. Peter felt strongly that his wife spent time trying to work out why she was diagnosed with cancer. He said *'we are strong on cause and effect aren't we as human beings?'* However, he acknowledged that it is difficult to find a cause for cancer. He believes *'this world is flawed and is just full of bad stuff as well as brilliant stuff and the rain falls on the just and the unjust'* – for him, it was a case of, sometimes, bad things happen to good people. Penny talked candidly about her perception of cancer: *'the word cancer is that word that sort of just grows in your mind, and you think that there is no survival from cancer.'* Interestingly, whilst Penny did not think that her friend spent much time thinking about why she developed cancer, Penny did: *'I was the one that questioned it, and I voiced my opinion as to why.'* They speculated together about whether her friend drank too much when she was younger or the fact that she used to smoke could be the cause. They also discussed the possibility of a hereditary link, but dismissed this. Penny concluded: *'we talked about it but nothing, nothing that she felt she'd done... I think that she had it and that was it.'*

Geoff talked about how common cancer seems to be today. He said *'something that was in quote "helpful" was that when his wife was diagnosed, society was beginning to realise that breast cancer was 'fairly common, that most women were going to be touched in that way.'* He said that his wife was also diagnosed at a time when people were beginning to talk more about cancer, so alongside a question of *'why me?'* there was also a sense of *'well this is something that most women will go through.'*

Few 'significant others' touched on specific reasons for the cancer diagnosis. The majority felt the cause was still unknown. However, potential causes mooted included previous trauma to the site of the cancer, and lifestyle factors such as additives and preservatives in food, alcohol and smoking. Amy said her mother thought her cancer was hereditary, and was quite accepting of the fact:

Amy: Do you know what? It's funny isn't it? You presume because Nan had it, "oh well, that's the reason why", it's hereditary sort of thing, or it's something, Nan's had, now I've got it and then she's sort of saying to me "you've got to be careful now, you've got to be careful, you're going to have to make sure you check yourself" so I think she was accepting of it. I suppose she did have times "why me?" "Why did I get this?" I'm sure she did have times like that but I think she was probably quite accepting of it. To a certain degree, like, "well, Nan had it. I've got it. And that's it."

Physical functioning and health

Some 'significant others' talked about the impact of cancer and its treatment on their loved ones' physical functioning. The consequences of cancer treatment impacted on their ability to engage in activities they had participated in prior to cancer. For example, some could not, or found it difficult to, carry on with certain hobbies or travel abroad. For example, George said *'in a practical sense [his wife] still suffers from some of the side effects of the chemotherapy. One of her hobbies is quilting. She finds threading needles sometimes difficult. That sort of thing. Sensation in the fingers.'*

According to Sheila, travelling abroad has been affected by complications experienced by her husband post-treatment. She described how her husband does not like to be too far from his local hospital, which she said was his *'safety net'*. As a result, they rarely travel abroad. This is clearly a frustration for her:

Sheila: I have got angry on occasion and sort of said, "oh why don't we go [abroad] where we went to before" but I can see he's sort of frightened of being away from his safety net i.e. the hospital, if ever he needed to go, within a couple of days. I mean, I do know hospitals where we used to go, because we went there for years but he is a bit more...

EB: Maybe a sense of continuity? Here they know him.

Sheila: Yes that's right and even if we were to move, he'd want to stay in this area cos of all the hospitals and people he's got to know.

'Significant others' also discussed how the overall health and mobility of those that had been diagnosed had deteriorated over time. Sheila feels her husband has aged, and his mobility has been affected by complications post-treatment:

Sheila: Well he's definitely changed in the fact that he's not as healthy as he was before and he can't do as much. I mean, I've noticed that more and more. He's having trouble coming up the stairs, he can't walk with me very far now, we used to go really long walks for an hour, well he'll just be gone probably about 15 minutes just across the field and back and then if you see him when he comes back he'll probably have to sit down because he'll be [huffs] you know.... So yes, it, yeah he's become a lot older, sometimes he does look like an old man.

Sheila said her husband seems to have more problems at night and gets very restless: *'at night it's worse, I think the body must, cos he's perhaps not moving around...'* As the following quote shows, Sheila is clearly worried about how much longer the side effects of treatment will continue, and the impact they have on her husband: *'I do fear there's only so long [he] can carry on. He does look very grey sometimes, and you know, you feel that, you can fight for so long...'*

Peter described a *'loss of confidence about health'*, and that they *'work hard, use all sorts of preventative things'* to stop his wife getting ill. That loss of confidence about health relates to the whole family, as both his wife and he are now worried about whether their daughter is more likely to develop cancer in the future.

Geoff talked about the implications of getting older, and how important it is to try to stay healthy. He said *'as you get older anyway, you realise that your body succumbs to all sorts of things that never bothered you before.'* He went on to say that, *'whilst we survived one thing, we don't have nine lives as it were. And we're no*

younger.' He also mentioned that, as he and his wife have both gotten older, cancer is a possibility for both of them: *'I certainly feel that, it occurred to me, it's not just [his wife]. And of course she's equally concerned.'* Geoff said that, as a result, they visit the doctor more quickly if they are concerned about their health, and try to look after themselves. However, in this respect, he said that now his wife has retired, she is less active: *'And I suppose when you're younger, you don't feel you need [exercise] so much whereas now, also the ease with which you put on weight and so on, it's all wrapped up in that kind of thing. The ultimate thing is to feel that you're not letting yourself go...'*

How 'significant others' perceive the person diagnosed with cancer today

In the interviews, we explored how 'significant others' perceive their loved ones today, in terms of who they are as a person, their outlook on life and their priorities. Some felt that cancer had had a profound effect on their loved one's identity, both positive, in terms of feeling stronger as a person, but also negative, for example with respect to the impact of cancer on one's body image and faith. Others said that cancer had reinforced an existing positive outlook on life or resulted in changed priorities. Some of those diagnosed had become involved in charity work or volunteering. 'Significant others' felt this provided those diagnosed with a different focus in their life, which had both positive and negative implications for their wider circle of family and friends. In terms of a more negative outlook, one 'significant other' discussed how planning ahead now suffers as a direct result of the cancer diagnosis.

Rachel felt that learning to deal with a cancer diagnosis, and more importantly, the legacy of cancer (particularly fear of recurrence) has made her husband a stronger person. Penny described how her friend has always been a strong person with an *'incredibly positive outlook on life'*, a *'real joy of living'* and a sense of humour, but cancer had perhaps made her a little more *'realistic'*:

Penny: I think... she's always been a strong person. I've always perceived her as a strong person. And I think that when there was a challenge over positive thinking, what happens if that's not enough, that actually really rocked me because I did think that she's the one who was always positive thinking, we can do this and everything's doable, well find a way round, and I thought that she was wobbling. But, you know, she's now, she's back to as she was before, still strong, still positive but perhaps a little more realistic.

Geoff described a '*steeliness*' that his wife demonstrated that he was not aware of; he saw a new side to her personality:

Geoff: Um, the thing that came out with this anger and things was the steeliness which was within her, which I kind of wasn't aware of. I suppose, the very superficial way of saying it is, that I would have said to you that she was a very nice person. And then suddenly you get this kind of steeliness and determination, and you think, "oh there's something a lot more here". When I say 'nice', there's also perhaps a certain lack of pushiness and yet there was this other side that really came forth and surprised me.

He also said that they were both less accepting of things that perhaps they would have gone along with in the past. It seems they are both more proactive in confronting situations that arise, not just sitting back and letting things happen. I think this is particularly in relation to health, as he later said: '*we've kind of learnt our lesson about not hanging around in terms of going to the doctor... you've still got to be vigilant, grab the opportunity to be tested.*' It seems Geoff and his wife have become more aware of a need to do this as they have gotten older. As Geoff said '*it's part of getting older but I suppose the other thing that you say is, well, we survived one thing, but we don't have nine lives as it were. And we're no younger.*'

Geoff: ...I suspect we're both more determined in the way we, when we're confronted with situations in life, all sorts of things. I think it's not only, I'm trying to think whether there was any, I suppose, again, we were generally lucky that there weren't any

situations that we were confronted with that really required us to dig deep. So, I suppose there's something that, to me, looking at her, a sort of step-change and, I mean, over the years, it was something that clicked into place, kind of built on that. Yes I suppose there's less accepting of things and more 'what can you do about it?' 'What can you make happen?' As a result of this.

From a more negative perspective, Peter felt that his wife's diagnosis '*dented her faith to some extent*' but that she remains a Christian.

Amy mentioned her mother's recent breast reduction, saying '*they're fantastic now. I think that was a little bit of an underlying issue with her then because obviously they looked, they were quite different sizes*' suggesting that, until recently, her mother had been unhappy with her body image. Penny said that her friend had '*an amazing philosophy. She believed that the cancer was in the breast and she had a radical mastectomy, and therefore it was removed from outside her body... psychologically she accepted that her breast had to go and that was it.*' She touched on her friend's issues of '*self-worth*' after her mastectomy. Penny described how her friend was '*well-endowed*' and therefore the removal of her breast '*was like a huge great hole for her*'. She said:

Penny: And you know, in hindsight now, she would have had a reconstruction, a reduction and a reconstruction. But that wasn't available to her when she had the cancer. So what she did was she compensated by sort of almost bringing her other breast around sort of around, and her shoulder around to sort of cover up that. And she would be constantly pulling, pulling at her jumper.

Penny also mentioned the ongoing discussion they have about reconstructive surgery:

Penny: And we go through the conversation about what about the operation that we discussed last year, about having a reduction, a reconstruction. But I think that every year she says no I don't want to do it, I don't want to go down there, but again it goes back to reopening the wound of actually having an operation on her breast. And I

think it's a very easy thing to say well I'll put it off until next year. And we've had the same conversation for so many years that I now know it's a conversation that she will have, but she won't be able to move forward to it. There's always something that gets in the way as to why she can't do it. I think that if she really, really wanted to do it, she would do it, because she's that kind of person.

Amy suggested that her mother has always led a full, independent life and was unsure whether cancer had changed her mother's perspective on life, as she was already such a positive person who *'embraced life anyway.'* However, later in our interview, she did say that perhaps cancer has changed her mother's outlook on life, because the outcome could have been so different. Ultimately, Amy feels that cancer has reinforced her mother's positive attitude to life, that she is lucky to have had such a good outcome, unlike others, and is therefore still able to do the things she wants to:

Amy: She's really independent. She always has been because obviously she's been on her own for quite a while and she is very independent, and maybe she does put an incredibly brave face on it sometimes but she does, she doesn't wait, I mean crikey we have to book an appointment to see her (laughs) so I think she's got a wonderful outlook to life now and maybe that is a positive thing from the cancer because, you know, it could all have gone so differently. But then again, as I said before, she's always been someone that's embraced life anyway.

Lucy spoke of how her mother took early retirement and, as a result, is enjoying life much more. Lucy feels her mother has *'kind of really sprung back from [cancer]'* but that taking early retirement was a *'turning point'* for her as she can now do what makes her happy, including working on her allotment and spending more time with her father. Lucy felt that taking early retirement gave her mother the opportunity to take stock and think about the difficult events that have happened in her life, not just her cancer diagnosis. Once she had *'some space to think about things'*, she was able to focus on what she enjoys doing and, according to Lucy she is now *'truly happy again'*.

Lucy: ...So I would probably say, a couple of years after her diagnosis she took early retirement and I think that was when she was probably truly happy again... I mean she got back to normal in the sense of yes, she went back to work, you know, does the jobs that everybody has to do and all that kind of thing, but in terms of, as I say, sort of being happy again, then that was then, probably a couple of years after her diagnosis.

EB: And was that in relation to her job or do you think it was still coming to terms with the fact that she'd had cancer and it took taking a step back from work as well...

Lucy: I think it probably did give her some space to think about things. As I say, obviously she had to look after my dad when he was ill and it kind of, I'm trying to think, I think about 6 or 7 years later, she was diagnosed, maybe 8 years, so it's not really all that long, you know, before she then had to deal with it herself. And I think, you know, it wasn't necessarily the job or place or anything cos, the fact was, her job came with private medical cover, which meant that she was able to have chemotherapy at home rather than having to go to the hospital every week, and that was a huge help really, you know, knowing that I didn't have to, or you didn't have to find somebody to take her to the hospital to sit with her and all the rest of it, so in some ways, the job helped out quite a lot, but I think when she took retirement, she was able to take a bit of a step back and just start doing, having a lot more time to do the things she really enjoyed, I think that was the big turning point for her.

Lucy also mentioned that if her mother wants to do something today, she will do it and does not keep things as a *'pipe dream'*. She said she was *'being a little bit more, not spur of the moment, but sort of, it there's something she wants to do, she'll save up and do it, whereas before she might have thought "oh no, I couldn't do that."'*

Lucy: ...I think it's probably made her little bit more, you know, some people sort of save up for a rainy day and stuff and maybe put things off a little bit, whereas she's now a little bit more "well, if I want to go on holiday now, I'm going to save up and I'm going to go." She doesn't try and keep things as a pipe dream I suppose.

Sheila said that family is the most important thing in her husband's life now:

Sheila: He writes letters to his children just in case anything happens, tells them he loves them and all this sort of thing, quite important because I suppose he wasn't told that sort of thing, but he sees what's important really and tries to sort of guide them, you know. You can see from all the photos, he's very, what's important is the family.

Describing a more negative outlook on life, Peter felt that long-term planning now suffers as a result of his wife's diagnosis, for example, planning holidays. He described how she is scared to plan ahead, for fear that something might happen which prevents them from doing what they hoped. This stemmed from the fact that they had to cancel a family holiday when his wife was diagnosed. He feels this *'left quite a bruise on [his wife]*.

Peter also talked about how his wife has developed her passion for helping others through her involvement with cancer charities. He said *'she can listen to these stories, you know which are very, very painful stories sometimes and very frightened stories of people who are a very difficult stages of cancer, of this particular cancer and probably won't survive. And how you help them to make, get them the best quality of life in the time they've got left'*. However, Peter also described the pressure his wife puts herself under. He feels she carries a *'heavy load'* as she listens and supports women with more advanced disease than herself. He feels his wife's involvement has given her *'a rather dark perspective on life... cos she hears and encounters the slice of life where the worst has happened'*.

Penny felt her friend had gained from being able to give something back, volunteering and fundraising for cancer charities, and supporting other women affected by breast cancer:

EB: I was wondering whether you would say that [she] felt that anything good had come out of having a cancer diagnosis, whether she'd gained anything as a result?

Penny: I suppose, I've never actually talked about anything good came out of it. But I suppose in a way there is, because she gave back, she did get involved with lots of charities. And I think sort of doing something like the trek that we did, I think that was, that was an emotional journey of returning, you know, giving something back. And again that was a lot of determination, but that was the group in itself, I think that the group that we were specifically with were a very determined group and a very supportive group. And I think that had she not had cancer, that would never had happened. And I think she learnt, sorry what she learnt was that there were certain things that were missing that she needed, and she certainly wanted to be able to give back, or to help other people who would be going through something similar to the experience that she went through.

Impact of cancer on relationships and communication

Most 'significant others' felt there was a greater closeness between themselves and the family member/friend who had been diagnosed, and that their relationships were stronger. For some this was because they have been a source of support but, for others, the greater closeness was due to the realisation that their loved one could have died. Communication has clearly improved in some relationships, partly through being forced to talk about, and manage, the consequences of treatment, or indeed through being more tolerant of one another. In terms of communication difficulties, a couple of 'significant others' mentioned how they felt their loved ones probably put on a façade at times and how sometimes the approach the 'significant other' took to support the person diagnosed was not always what the person diagnosed wanted or needed. Roles appear to have changed within some families, with both positive and negative implications. Only one 'significant other' touched on, albeit briefly, the impact of cancer on intimacy and their physical relationship. One husband said that his wife's diagnosis had not affected their physical relationship, and that they were both happy in that respect.

Peter was more vocal about the impact cancer has had on their relationship than his wife. From his interview, it appears cancer has had quite a positive effect on

their relationship. He described himself as an optimist whilst both his wife and he described her as a pessimist. Peter said that they *'balance each other out'* as a result. He also said that he is immensely proud of his wife, and the work she does. He thought they had gained from the experience. In particular, he said he had *'gained a partnership with a wife who's doing a very enriching and fulfilling work which I'm very proud. I think it's great. Though it's not always easy... It's nice that what was a bad thing has ended up being used for good, to enrich and help other people's lives'*. Rachel suggested that the disease had strengthened the relationship: *'I think it's made us stronger now, but going through it at the time was very difficult.'* George suggested that he and his wife *'might have become closer'* – but that it was difficult to know whether that was because of the cancer, or the passage of time. Amy felt she and her mother had become closer as a result of cancer, but that they were close before. The daughter described how they adopted the approach *"we're in this together"* and *"we do this together"*.

Sheila said that it had been therapeutic for her husband to talk about cancer and the side effects he was experiencing. She felt that they had become closer, partly because they had to talk a lot more about the consequences of cancer treatment. In this respect they appeared to be very open with each other about the impact side effects were having on their family. In contrast, Amy said that she and her mother made a good team and that she would *'like to think that [her mother] would have told me if she needed me. I'm sure she would. That's what she's like.'* However, Amy also said that her mother would probably have put on a façade at times: *'I imagine she would have had some quite bad times and just then put on a smiley face and gone "oh yeah, yeah, yeah, I'm alright."'* She suggested her mother did this because *'you [don't] want to let your fears be known to anyone else, because they are so horrible.'* In this respect, whilst Amy felt her mother shared a lot with her regarding how she was feeling (*'she is very open with me, she tells me how she feels. And always has done'*), she acknowledged that her mother might not have shared

everything: *'I'm sure she had some points when she was on her own and she really did fall apart and I probably won't ever know that she felt like that.'*

Penny was clearly someone her friend could talk to honestly and openly, sharing her feelings and emotions, even if they disagreed or were difficult to deal with. As Penny said, *'And I remember saying to her you've just got to be positive, you've just got to be positive. And she just looked at me, [with] so much anger, and she said "well what happens if being positive just isn't enough?" And I just didn't have an answer for that one.'*

In terms of role changes, Sheila felt she had taken on a mother-type role and had to be strong for her husband, as her husband constantly lives in fear, particularly with regard to the side effects he experiences, and an ongoing fear of recurrence. Sheila said *'you have to be a bit firm sometimes, yeah, firm to be kind... be a bit more, you know, "no, you can do this," "come on, we're going to go for a walk," "be quiet, it will be fine the next day," you know, I have to be strong really.'*

Peter acknowledged that the direction of their lives had changed as a result of his wife's involvement in cancer charity work, suggesting it *'has changed our lives hugely in that her work is supporting others now which, being the nature, both of us are bit like this, I mean work doesn't stay at work, it's all over the place. So cancer is, and her work with those who have been diagnosed or suffering, is a big part of our, both of our lives'*.

The future

Generally speaking, 'significant others' seemed to be quite positive about the future, all the while acknowledging that cancer, both the disease itself and the

experience of it, is something those diagnosed will always carry with them – particularly the risk and fear of recurrence.

Amy thinks her mother's future looks very positive. She described her mother as independent and someone who embraces life, and feels she will have a busy and fulfilling future:

Amy: Oh it's bright and breezy. She can go and do what she wants. She really is very much like that. Nothing, if she gets something in her head, a few years ago she did the Three Peaks Challenge, nothing worries her. She's got a good social life and she went abroad for her 60th. She did all that on her own and things like that, she's brilliant my mum, really. Absolutely brilliant. I don't really ever tend to worry about her very much. That's really horrible isn't it? (laughs).

Peter said his wife is reminded through her involvement with other people affected by cancer that the disease can return. In this respect, he feels his wife is pessimistic about their health and, as such, does not feel optimistic about the future. However, he, being an optimist, feels *'there's lots of new adventures to explore'*.

Sheila worries about the future as a result of her husband's fear of recurrence and the impact of ongoing consequences of treatment. However, towards the end of the interview, when I asked her about the future, Sheila seemed quite hopeful, not just in terms of her husband overcoming the side effects he experiences, but that they might get back to enjoying some of the activities they had previously done together, including travelling overseas. She said it is their hope that *'normal'* life can resume.

Sheila: Well, obviously we hope that he will carry on into an old age... obviously if he can, he has gone a week or so before without using a catheter and that's great 'cos there's no infection, and you think 'wow, he might actually be able to come back on a buggy to play 9 holes of golf' or something (laughs) which would be great... Something

that we did together. It would make him feel like, you know, a normal activity, that a man does. I'm just hoping that will happen later on really.

Penny feels that she and her friend will continue to have conversations about reconstructive surgery: *'...I think it's a very easy thing to say well I'll put it off until next year. And we've had the same conversation for so many years that I now know it's a conversation that she will have, but she won't be able to move forward to it. There's always something that gets in the way as to why she can't do it.'* However, her perception of her friend's future is highlighted in the passage below. Penny feels her friend views the future positively, and has learnt to accept what has happened to her:

Penny: The future, I feel, my experience is that cancer will always be with [her] because that is a huge experience that she's been through, but it is certainly not, it's not the first thing that she thinks of in the morning and the last thing at night. She's learnt to live with what's happened to her, and she's moving forward. I mean she's talking about when we're 80, so that, the future goes on, stretches on. It makes me laugh but she's got this rescue dog and she was saying to me do you realise that if he lives as long as he should do, I'll be 80? That's how positive she is.

Summary and next steps

The 'significant others' interviewed described the positive and negative impact of cancer on their loved ones' sense of self, relationships and life priorities. The positive impact included a perception that those diagnosed were stronger, more determined and less accepting of things. Being able to give something back and supporting other people with cancer, a closer relationship with their loved ones, and a positive, proactive approach to life were also highlighted. The negative impact of cancer described by 'significant others' was felt either directly by the person diagnosed, or more widely by those close to them. This included not being able to engaged in activities they once did, a nervousness about travel, not feeling

confident to plan for the future, a loss of confidence about health in general, ongoing body image concerns, and the uncertainty associated with getting older (in terms of broader health issues, mobility and maintaining independence). 'Significant others' appeared relatively positive about the future. However, several acknowledged that cancer, both the disease itself and the experience of it, is something those diagnosed will always carry with them – particularly the fear of recurrence.

The next chapter presents the cross-case analysis, exploring similarities and differences in the stories shared by those diagnosed with cancer, and comparing and contrasting these accounts with those presented by the 'significant others' interviewed. The aim of the cross-case analysis is to describe the experience of long-term survivorship at the aggregate level, through the identification of common themes across the cases.

Chapter 9. The experience of long-term cancer survivorship: Findings from the cross-case analysis

Introduction

This chapter presents findings from the cross-case analysis. Individual-case findings from those diagnosed with cancer were merged by searching for overarching themes in the unique 'restored' accounts (See Figure 5.9, p. 159). Merging findings is useful when understanding the quintain³⁵ - in this study, the experience of long-term cancer survivorship as a whole - is more important than the individual cases, but where some contextual understanding is still desired. The chapter also compares and contrasts the accounts of those diagnosed with cancer and the 'significant others' involved in the study. This analysis serves to highlight instances where accounts shared by those diagnosed and their loved ones differ and explores what the implications of these contrasting accounts might be.

The chapter first describes how cancer has left a legacy of benefits and losses for the participants in this study. In particular, *a legacy of lingering uncertainty* is evident across cases, and is supported by the accounts of both those diagnosed and 'significant others'. I then go onto describe a typology of the place of cancer identified in the findings whereby cancer is situated in the *past*, *past-present* or *present-future* and is presented from the perspective of both those diagnosed and the 'significant others' interviewed. The legacy of lingering uncertainty, along with various '*reality checks*' (reminders of cancer), influences the place of cancer in the lives of those living long-term after a cancer diagnosis. As a result, the place of cancer is dynamic, oscillating between the past, present and future, and foreground and background of participants' lives. In terms of differences evident in the narratives of those diagnosed and the 'significant others', I discuss contrasting

³⁵ The individual cases share a common characteristic. They may be members of a group or examples of a phenomenon. This group or category is called the quintain (Stake, 2006).

accounts of the implications of the restrictions cancer places on individuals' lives, communication between loved ones, whether or not the individual diagnosed continues to search for the cause of cancer and the perceived place of cancer in the lives of those diagnosed. I draw the chapter to a close by discussing the findings in relation to existing research. In particular, I highlight how the findings could be used to build on existing models of survivorship, incorporating the oscillating, shifting and situated place of cancer in the lives of those living long-term after diagnosis.

The legacy of cancer

Kate and Moira both mentioned that cancer has left a '*legacy*'. A legacy is defined as 'anything handed down from the past'³⁶. This led me to consider the legacy of cancer experienced by the thirteen participants in the study. In this section, I describe the legacy of cancer through a discussion of the *benefits* and *losses* experienced by long-term survivors during this phase of the survivorship trajectory.

EB (first interview): And how do you feel coming up to that [follow-up] appointment?

Moira: Nervous. You do, you feel very nervous. I try not to think about it too much but... it makes me very nervous, a couple of days beforehand because, of the very nature of that kind of cancer, that you don't feel ill. So you can be perfectly alright and then you get this diagnosis, which is how I got my diagnosis in the first place. So I think that's a legacy that probably makes me feel nervous.

Kate (follow-up interview): ...I used to be ashamed about what had happened to my body and I don't know yet if I accept what has happened to my sexuality, I wouldn't say I've accepted it. So sorry I've been saying everything's all glass half-full but that is an enduring legacy and a major one and I don't know what to do about it, and it's going to have a major effect on my future.

³⁶ <http://dictionary.reference.com/browse/legacy> [Accessed July 11th 2012]

Benefits experienced during long-term cancer survivorship

All thirteen participants mentioned that something good had come out of what was a bad experience. However, what that 'something good' was differed across cases. Participants described gains with respect to their sense of self, outlook on life and relationships, benefits as a result of their involvement with cancer charities and improvements to their lifestyles.

Relationships

Mary and Kate discussed how they now understand the importance of nurturing friendships, as they are an important source of support, both for themselves and their families. Research by Greenwald and McCorkle (2007) also found that long-term cervical cancer survivors put more effort into relationships. A broader literature review on post-traumatic stress and growth in cancer survivorship also reported that cancer survivors invest increased time and effort in relationships (Jim and Jacobsen, 2008). Most participants feel they are closer to family members and/or their partners. For some, the future is now focused on their families; they are their most important priority. For example, Richard, Mary and Janet talked about wanting to live to see their children marry. Mary and Janet also mentioned how important it is to be a pro-active grandparent, sharing their values with their grandchildren. The majority of 'significant others' also felt there was a greater closeness between them and their loved ones, and that their relationships were stronger as a result of the cancer experience. Communication had improved in several relationships, partly through being forced to talk about, and manage, the consequences of treatment.

Previous research has also reported that positive aspects of the cancer experience include long-term survivors becoming closer to family and friends, and more appreciative of their time together (Foley *et al.* 2006). Richard and Margaret

suggested that they are also more appreciative of other people's pressures and sensitive to other people's situations – more so than they were prior to their diagnoses.

Self

Most participants described how they have changed as a person, often for the better, as a result of cancer, albeit often within the context of other life events and their life stage. Several participants said they feel stronger and more confident as a result of the cancer experience. For example, Patricia said that cancer has '*hardened her up*' - she does not let people '*trample*' over her like they used to. A couple of 'significant others' also felt cancer had a profound effect on their loved ones, making them stronger as a person. Other studies have highlighted that survivors report increased inner strength after a cancer diagnosis: they are more outspoken, decisive, confident, assertive, independent and less dependent on the approval of others during long-term survivorship (McGrath 2004b, Schroevers *et al.* 2006, Mols *et al.* 2009b, Lelorain *et al.* 2010, Schroevers *et al.* 2011, Hubbard and Forbat 2012). Horgan *et al.* (2011) found that increased self-confidence appeared to emerge from reflecting on how breast cancer survivors managed the illness³⁷, and from concluding that they had been courageous in doing so. Indeed, Angela feels that, through surviving cancer and other life events, such as divorce and other health concerns, she has '*earned*' a new-found confidence and strength. She said '*you feel quite proud of the way you've dealt with it, the way that you've let other people see that it hasn't got you.*' Participants also suggested that they are kinder, a better parent and partner, and less selfish around those close to them. Some also feel that they are more laid back as a result of their diagnosis, with Claire saying she is less '*Little Miss OCD*' today.

³⁷ Breast cancer survivors were a mean of 4 years, 8 months post-diagnosis

In terms of their outlook on life, some participants talked about how their priorities have changed. For example, Kate said her priorities are '*crystal clear*' now. Facing cancer, and death, helped them put other life events into perspective. Cancer allowed Margaret to take stock. She said that facing death has enabled her to put things into perspective. Others said that they try not to let the little things bother them now. Around half of the 'significant others' said cancer had reinforced an existing positive outlook on life or resulted in changed priorities. Previous research has also reported that survivors reprioritise goals, for example, life goals over career, and focus on the important things in life (Carter 1993, Shapiro *et al.* 1997, Dow *et al.* 1999, Tomich *et al.* 2005, Bishop *et al.* 2011, Kahana *et al.* 2011). Indeed, Richard said he has '*encapsulated*' his life. It is more focused on family, with less attention paid to the people on the periphery, or activities that he does not want to participate in. Participants are appreciative of life and how precious it is. Several described how they no longer take life for granted, and adopt a '*get out and do*' approach. These findings resonate with those reported by Rasmussen and Elverdam (2007) who found that the confrontation with death leads cancer survivors³⁸ to appropriate time. They prioritise how and with whom they spend their time, usually focusing on family and friends. They also prioritise their own wants and needs, and are quicker at seeing through people to decide what kind of person they are. Prioritising who they spend time with, and what activities they engage in, is a way of taking control of time, as life is now more uncertain (Rasmussen and Elverdam 2007).

Cancer charity involvement and peer support

Most participants are involved in some way with cancer charities. They described benefits to volunteering, fundraising, or working for these organisations. Involvement provides an opportunity to meet new people, and form new relationships. Moira and Patricia said they have met '*lovely*' people as a result of

³⁸ The sample included survivors living in the acute through to extended survivorship phases

their diagnoses which, according to them, is an unexpected benefit of entering the cancer 'world'. Moira described how she feels a 'connection' with other women with breast cancer. Other studies have found that survivors 'connect' with a range of people that they would not have met had it not been for the cancer experience (McGrath 2004a). Meeting people further 'down the line', as Patricia put it, provides a confidence boost and is a source of reassurance. Morris *et al.* (2011) found that the opportunity to form a connection with other survivors solidified their self-perception as a cancer survivor. Equally, comparing themselves to other survivors helped women re-evaluate their own situation more positively – seeing other survivors doing well gave the women strength and confidence. This was certainly the case for some of the women in this study. Here we see evidence of the positive impact of upward social comparison. Social comparison theory posits that 'being able to compare one's own experience with similar others may normalise the experience, provide positive role modelling, encourage health promoting behaviours and enhance self-esteem' (Campbell *et al.*, 2004: 3). Upward comparison with those who have survived cancer can lead to hope and optimism, self-improvement and a 'can-do' attitude (Campbell *et al.* 2004).

Involvement in projects, such as patient experience groups, has been both productive and rewarding to some participants, whilst others hope to save lives by raising awareness about cancer and campaigning for improved screening. Some participants mentioned that they get a sense of satisfaction from volunteering, for example, Richard talked about the pride he feels at being involved with cancer charities. He, like Moira, Sue and Claire, feels that he is giving something back to the cancer community and, in a sense, *should* give something back as time, money and effort was spent treating him. Moira and Richard referred to this phase of survivorship as 'payback time'. A few 'significant others' talked about how charity work or volunteering provided their loved ones with a different focus in their lives. For example, one husband said his wife now has a 'passion' for helping others and feels she now has a purpose in life. McGrath (2004a) also found that survivors' feel

a desire to make a difference to the lives of other people affected by cancer, for example, through volunteer work.

The activities participants are involved in have provided them with a host of new experiences, such as giving presentations, appearing on television and participating in fundraising activities. For some, their involvement is a way to keep their minds active and distract them from the ongoing consequences of treatment. For example, by campaigning for a national screening programme, Richard feels that he has a purpose, and by reviewing literature for a cancer charity, Malcolm and Janet keep up-to-date with clinical developments and gain valuable information about their own cancer.

Lifestyle

Several participants said they are healthier today, engaging in physical activity and following a healthy diet. Some have to do this to manage the impact of cancer treatment on their bowel and/or bladder function but others have adopted a healthy lifestyle as a way to manage the risk and fear of recurrence. A more detailed discussion of lifestyle changes associated with risk and fear of recurrence is presented later in this chapter.

Losses experienced during long-term cancer survivorship

Whilst all thirteen survivors described benefits or gains, they have also experienced losses as a result of cancer. Cancer has had a negative impact on participants' sense of self, outlook on life, relationships and physical functioning.

Relationships

A literature review by O'Mahoney and Carroll (1997) reported that a diagnosis of breast cancer affects partners' communication, their sexual relationship and role identities. They suggested that the strongest predictor of problems in relationships after a cancer diagnosis is the quality of the relationship prior to diagnosis. Patricia and Kate experienced marital breakdown post-treatment. In support of O'Mahoney and Carroll's (1997) assertion, both had problems in their relationships prior to diagnosis, however cancer seems to have been a catalyst for the breakdown of these relationships.

Loss of sexual functioning, and relationship and intimacy concerns, were dealt with in different ways by the survivors in this study. Roger sought advice, discussing his concerns with his consultant who referred him to a sexual therapist, whilst Kate does not know where to go for advice and support and Malcolm ignores the problem. In their commentary of social well-being after cancer, Hara and Blum (2009) commented that survivors sometimes perceive themselves as 'damaged goods' which 'complicates their attempts to pursue or re-establish intimate relationships' (2009: 3). This is certainly the case for Kate, who described how she '*divorced*' herself from her lower body after treatment, and feels that others perceive cervical cancer as a '*dirty cancer*'. This makes embarking on a new relationship frightening as, at some point, she will have to share her cancer experiences with a new partner and is worried about their reaction.

Few participants reported a lack of understanding from those close to them, although some did mention that their loved ones would not be able to understand what they have been through because they have not been through cancer themselves. Related to this, a couple of 'significant others' commented that their loved ones probably put on a façade at times. They interpreted this as the person diagnosed trying to protect them from what they were experiencing or feeling. In

some cases this did appear to be the case but in others the façade was related to those diagnosed not wanting to talk about how they were feeling because they did not feel their loved ones would understand.

Of the 'significant others' I spoke to, there did not seem to be evidence of them perceiving those diagnosed as 'omens of hazard' (McKenzie and Crouch 2004) or avoiding discussions about cancer and its consequences. If anything, it was those diagnosed that avoided talking to their loved ones about how they were feeling, either for fear of upsetting or worrying them, or perceiving that their 'significant other' found it difficult to talk about cancer. This being said, there was an example in the study of what Horlick-Jones (2011) referred to as 'compassion fatigue'. Malcolm mentioned that some of his friends have '*cancer fatigue*' where they no longer want to hear him talk about his cancer experience. It could be that, to them, Malcolm is an 'unwelcome omen of hazard' where voicing concerns or fears about cancer is discouraged (McKenzie and Crouch 2004).

Roles and priorities appear to have changed within a couple of families, with one wife in particular saying that she now takes on a 'mother-type' role and has to be strong for her husband because he is fearful of recurrence and the ongoing side effects of treatment.

Further discussion of the impact on relationships, in particular, whether those living long-term after a cancer diagnosis experience Little *et al.*'s (1998) liminal element of 'communicative alienation', is presented in the discussion (Chapter 10).

Self

Several participants, including Sue, Mary, Moira and Andy, described a loss of confidence regarding their health. They fear cancer recurrence when they are ill, in part because they did not feel ill when they were diagnosed. Sue and her husband

described how she is slightly obsessive about preventing the spread of illness today, perhaps because when she is ill, it takes her longer to recover.

Loss of confidence regarding one's body image was discussed by a minority of participants and their 'significant others'. Moira described how she is more self-conscious in the summer, when she is out in public wearing a swimming costume, as she is acutely aware that others can see she has had a mastectomy. During the summer, her private self (which she has come to terms with) is thrust into the public, which serves to remind her that she had breast cancer. The wider breast cancer literature talks about how women might feel 'marked' by the disease (Langellier 2001). I would argue that this is the case for Moira, but primarily when her body is on public view. In contrast, Patricia wondered how different she might feel had she not had a reconstruction. A successful reconstruction was a key turning point for her as she was able to establish a '*new me*'. She said she was '*back to what I was. It's not real, but it's, it is real in another way.*' The impact of losing a testicle did not appear to affect Andy at this point in his survivorship trajectory. This is in contrast to a study by Skoogh *et al.* (2011) who found that long-term survivors of testicular cancer who had undergone an orchidectomy experienced feelings of loss, uneasiness and shame, particularly if they had not been offered a prosthesis. Andy was given a prosthesis and, although he initially experienced different sensations, he has been able to remain sexually active. His sense of masculinity is maintained because he was able to have children, but also because only one testicle was removed. He speculated that he would have felt emasculated if both testicles had been removed. Finally, Kate described how she felt maimed by her cancer diagnosis and treatment; that a '*nuclear war*' had occurred in her pelvic region. These feelings have abated over time but they still affect how she feels about herself today, and that has implications for her ability to engage in a new relationship.

Other perceived negative implications of cancer on self described by 'significant others' included the impact cancer has had on faith, with one husband saying that

his wife's faith has been 'dented' by cancer. In terms of outlook, one 'significant other' discussed how planning ahead now suffers as a direct result of the cancer diagnosis. One husband felt that his wife did not want to plan for the future in case something happened which would prevent them from doing what they had intended.

Consequences of cancer and its treatment - implications for physical functioning

The main negative consequence of cancer and its treatment during the long-term survivorship phase is ongoing impaired physical functioning. Based on a review of longitudinal and cross-sectional data, Harrington *et al.* (2010) found that cancer survivors sometimes experience consequences of treatment more than ten years post-treatment. As the title of their review clearly reveals: *'It's not over when it's over'* (Harrington *et al.* 2010). Macmillan Cancer Support also highlighted the long-term consequences of cancer and its treatment in a report titled *'Cured - but at what cost?'* (2013). The report highlights that whilst there are over two million people living with cancer in the UK today, not all of them are 'living well'. Some long-term and late effects of cancer and its treatment were reported by participants in this study, including *'chemo-fever'* (fatigue) which prevents Sue from working full-time and engaging in an active social life; *'chemo-brain'* which forced Malcolm to retire; loss of sensation in the fingers, which prevents several participants from carrying out tasks such as threading a needle; impaired bladder and bowel function; lymphoedema and bone-thinning, which can cause discomfort and pain, and even prevent individuals from carrying out physical activities. A minority of 'significant others' also described how the consequences of cancer and its treatment impacted on their loved ones' ability to engage in certain activities they had participated in prior to cancer.

This being said, most of the participants in this study are able to go about their daily lives despite these ongoing consequences of treatment, which they may experience

daily or intermittently. For example, both Malcolm and Janet have recovered well after colorectal cancer, establishing normal eating and bowel habits (as per Rozmovits and Ziebland, 2004) but from time-to-time they may experience the consequences of surgery, such as a need to rush to the toilet as a result of something they ate. In Janet and Kate's cases, the lasting legacy of their diagnosis is checking for blood every day. Taylor *et al.* (2011) refer to this as 'guarding' – heightened monitoring for signs and symptoms. Survivors adopt new behaviours to have a more dependable and controlled body (Taylor *et al.* 2010). Katie, Janet and Malcolm have learnt over the years to avoid certain foods to manage the consequences of surgery on bowel functioning.

The consequences of treatment also impact on travel, which was something discussed by both those diagnosed and their 'significant others'. Richard and Malcolm talked about how their ability to travel is limited. Long-haul flights are out of the question, in part due to the need to take various pieces of medical equipment with them and the need to be close to a private toilet. For Richard, I think a desire to be close to his medical team is also a contributing factor.

Legacy of lingering uncertainty

Through the cross-case analysis, I identified a core theme underpinning the cancer narratives. An underlying sense of *lingering uncertainty* was evident in all of the participants' accounts. Much of the uncertainty is linked to concerns for the future, however, it manifests itself in different ways and to different extents from participant to participant. The main manifestation of lingering uncertainty is an awareness, by all in the study, of the possibility of cancer recurrence. Further discussion of this, and other manifestations of lingering uncertainty, is presented below.

Risk and fear of recurrence

Concerns about recurrence were evident in all of the cancer narratives. However, the extent of these concerns differs from participant to participant, as do the ways they manage the risk of recurrence (actions), cope with the anxiety/fear of recurrence (strategies), and the resultant impact of these concerns during the long-term survivorship phase. Fear of recurrence seems to range from a general acknowledgment that individuals could be touched by cancer again, but it is not something that prays on their mind, through to a strong sense that cancer will come back. Fear of recurrence can relate to recurrence of the same cancer, a second cancer due to treatments received or metastatic disease, and this also differs across accounts.

The risk and fear of recurrence prays on the minds of Janet, Mary, Kate, Andy and Richard. As already discussed in her 'restoried' account, Janet described a '*niggling little fear*' about recurrence, which stems from the fact that she does not know what caused her cancer. As such, she said she does not know what to do to prevent it from returning. Janet also feels she is '*prone*' to cancer as a result of other cancer episodes experienced by her and her family. Mary said she feels she is more likely than not to get cancer again. She feels unsure about the signs and symptoms of recurrence to look out for, which adds to the uncertainty. She recently experienced a persistent pain in her stomach, for which she was undergoing tests at the time of our follow-up interview. Kate described a fear of recurrence that is compounded by the fact that she has started smoking again. She feels that God will punish her for squandering her second chance at life. She experiences '*spikes*' of fear, for example, when she smokes or feels a pain in the site of her cancer. Andy has an ongoing fear of recurrence, linked to the fact that he feels cancer is the disease that everyone in his family dies from. This is despite healthcare professionals telling him he was cured. He feels that cancer is within you, potentially '*brewing*'. Even now, fifteen years post-treatment, when he is ill, Andy's first thought is that cancer has come

back. Finally, Richard feels he can only say he is free of cancer '*at the moment*' – he will never be totally free, and fears cancer will '*pop up*' somewhere at some point.

EB (follow-up interview): ...I was just wondering whether you worry today about recurrence?

Kate: I do, I do, I do. I do worry about that and I worry about the fact that the treatment, you know, the chemo radiation... oh sorry, going back to your last question and how I feel today, of course, chemo radiation has, carries a risk of bowel cancer later on, recurring cancers in the pelvic region, caused by the chemo radiation, so that's another reason, you know, I'm pretty upset I had chemo radiation rather than surgery... I became, there was one thing in favour of having the chemo radiation, in that someone said it sterilises the whole area, that was doctor speak again, so I sort of felt, in some ways, it felt like there had been a nuclear war in my pants... I suppose it's more safe from recurrence from that point of view. But in the early years I was obsessed with recurrence, I was terrified. Every time I had a pain I was, you know. I mean if I have a pain now, you know, it always flashes through my mind, is it a recurrence, and they say if it's still there in 2 weeks, you know and it never is, touch wood.

For the majority of the participants in this study, there is an acknowledgement that cancer could come back, but they do not dwell on it or let it prey on their minds. Malcolm said he does not feel there are any '*lingering*' cells in his body that could cause a recurrence. Margaret feels that if cancer does come back, it will not be in her breast as she was successfully treated for that cancer. Patricia did not appear worried about recurrence, although she acknowledged that cancer could come back. She feels that she has had her '*turn*'. Equally, Angela is not scared that cancer will come back, but is aware that it could, highlighting the experience of a friend who had a recurrence nine years after her first diagnosis. Claire feels that her risk of developing cancer is now the same as everyone else. Moira said cancer does not keep her up at night however, she said that if she were diagnosed again, unlike her doctors who would say it was a '*new*' cancer, she would feel it was related to her original diagnosis.

Sue is aware of the long-term implications of some of the treatments she received, for example, that she is now vulnerable to other cancers. However, her job provides her with a '*rational knowledge*' of ovarian cancer, which helps lessen her concerns about what might happen in the future. Also, linked to the fact that she was diagnosed with early stage ovarian cancer, she knows from talking to other women that it could have been worse, and that her future is brighter than that of women diagnosed with more advanced cancer. Finally, whilst Roger did not talk specifically about his fears of recurrence, recent reengagement with the healthcare system for a PSA test demonstrates that he is still concerned about recurrence eleven years post-treatment. Angela, Moira, Claire and Patricia all mentioned that if they were diagnosed again, they feel they would be able to deal with it. Angela said she knows what to expect now, and Moira, Claire and Patricia hoped they would cope in the same way they did the first time.

Patricia (follow-up interview): ...I don't sort of think "oh gosh, it's going to come back". If it does, I got through it once and there's no reason why I wouldn't get through it again. But I think if it was going to come back it would have come back between the two and five years, although I have heard people, there was somebody who it's recurred five times. But I don't sort of worry about it now.

As the most common manifestation of lingering uncertainty, Figures 9.1 and 9.2 highlight strategies participants employ to cope with the ongoing fear of recurrence, and manage the risk of recurrence. The actions and strategies highlighted here are a combination of those mentioned specifically by participants, but also those interpreted as such through my analysis.

Figure 9.1: Strategies for coping with the fear of recurrence

Awareness of symptoms of recurrence: checking breasts, for blood, etc.
Keeping busy/distractions
Seeking information/advice
Attending screening/follow-up: reassurance, feeling they are being monitored
Comparing themselves to others: feeling they had been diagnosed with a 'good' cancer
Giving it time: fear recedes over time, learning to live with it
Adopting a positive attitude: thinking they would deal with recurrence in the same way as the original diagnosis, fighting spirit
Acknowledging that cancer was caught early

Figure 9.2: Strategies for managing the risk of recurrence

Giving it time: awareness that risk is reduced with time since diagnosis
Following treatment protocols e.g. Arimidex, Tamoxifen, avoiding HRT
Seeking information/advice
Acknowledging that the site of cancer has been removed, thus feeling it will not come back there e.g. hysterectomy; prostatectomy, mastectomy, etc.
Trying to ascertain the cause of cancer and then eliminating the contributing factors
Managing diet/lifestyle: reduce stress, remain active, maintain a healthy weight, eat five-a-day, eat less fatty food, eat less red meat, reduce alcohol intake, drink pomegranate juice
Attending screening/follow-up: reassurance, feeling they are being monitored

Several participants talked about how their fear of recurrence has abated over time. Kate said that time does its '*usual healing thing*' and the fear of recurrence has lessened over time. However, she does experience '*spikes*' of fear, for example, when she feels a pain or when she smokes. As Andy put it, you have to '*learn to deal*' with the fear, and that can only be achieved by giving it time.

The perception of cause appears linked to the strategies individuals employ to manage that risk and fear. Margaret and Mary perceived stress to be a causal factor in their diagnosis so they actively attempt to reduce the amount of stress in their lives. For example, Mary has just resumed meditation, taking time out of her busy day to focus on herself. Kate speculated that HPV was the cause of her cervical

cancer. Based on her perception of the cause of cancer, Kate manages her risk by not engaging in an intimate relationship.

Identifying how to manage the risk of recurrence has been particularly difficult for those who have not been able to find a cause or explanation for their cancer. However, a positive to this is that some participants, including Janet and Richard, have adopted a healthy lifestyle regardless – as a way of doing something to try and prevent recurrence. Janet mentioned that she eats more than the recommended ‘five a day’ and remains active as she has read that poor diet and being overweight are risk factors for colorectal cancer. Richard drinks pomegranate juice as he read that it might reduce the risk of prostate cancer recurrence. He said *‘I’m doing my best to make sure the damn thing doesn’t come back.’*

However, ‘knowing’ the cause of cancer does not necessarily reduce the fear that it might come back, even if there appears to be a way to prevent it. For example, Margaret manages stress in her life and, as a result, cancer does not worry her day-to-day. On the other hand, Kate continues to experience a strong fear of recurrence, despite perceiving HPV to be the cause of cervical cancer and not engaging in sexual activity which she believed spread HPV. As such, there is no discernible pattern between perception of cause and fear of recurrence. This being said, those who have no idea why they were diagnosed with cancer continue to experience a strong fear of recurrence, which is understandable as they can only speculate about what they can do to reduce their risk of it coming back.

Will cancer be my cause of death?

Cancer has compounded Andy’s fear of death and dying and, as such, he has a bleaker view of the future. He feels that cancer will *‘rear its head’* again, as several family members have died from cancer. Also, his perception of cancer as a little *‘pinhead floating around in your body’*, which then settles and develops mean he

feels cancer is potentially '*brewing*' within him. As already discussed, Janet feels '*prone*' to cancer as a result of cancer deaths in her family and the cancer episodes she has personally experienced. As such, she has a '*niggling fear*' of recurrence. Andy and Janet feel, therefore, that cancer is the disease in their family and will ultimately be their cause of death.

Will side effects continue indefinitely?

For several participants, the ongoing consequences of cancer treatment are a source of uncertainty and have the potential to affect their futures. Sue described how she has to '*live within her boundaries*' today, and that '*chemo-fever*' means that she cannot push herself:

EB (follow-up interview): You also mentioned that you feel that you have to live within your boundaries more, you mentioned the tiredness, and what you can do day-to-day. Do you experience any other boundaries, is there anything else you feel restricts what you do day-to-day now?

Sue: I think it's the tiredness and the getting ill quickly if I become overtired is the main sort of thing that's left over. Just having to pace yourself all the time, and just being aware that you have to look after yourself a bit more than you otherwise would. Cos you don't know what's around the corner. But on the other hand, you don't know what's around the corner but you've got to pace yourself cos you probably are cured so you've got quite a bit of your life left and you've got to be well enough to deal with that. If that makes sense?

As already mentioned, Richard experiences ongoing urological problems. Of concern is that he could develop a resistance to the antibiotics he is prescribed to clear the infections he develops as a result of self-catheterisation. If the urological problems continue, Richard's life will be restricted by his immobility, inability to travel long distances and requirement to be near a clean, private toilet at all times. However, thinking positively, Richard said that if he can overcome the urological

problems he experiences, he will be able to engage in some of the activities he had done previously.

Future sexual function and relationships

Patricia and Kate talked about the legacy of cancer on their relationships, with both wondering whether they will meet a new partner. Patricia's marriage broke down, in part, as a result of her cancer diagnosis. She was divorced around the five-year point and, as a consequence, moved to be closer to her children and grandchildren. However, despite an active social life, Patricia said she is lonely and would like to meet someone to share her life with. Ongoing sexual functioning and relationship issues cloud Kate's future. She associates sex with death, due to the potential spread of HPV, which she feels was the cause of her cervical cancer. Kate has not fully accepted what has happened to her body and sexuality and wonders if she will have another sexual relationship. She admitted that this legacy will have bearing on her future.

Children's risk of developing cancer

Over half of the participants in the study described a sense of lingering uncertainty for their 'significant others'. Andy, Janet, Richard, Sue, Mary, Angela and Moira all voiced concerns about the fact that they may have influenced their children's risk of developing cancer in the future. For this they feel guilty. Richard said that he would '*badger*' his son to have a PSA test. Mary is worried that she has passed on '*bad genes*' to her children. However, from a positive perspective, Janet said it is reassuring to know that her cancer is not hereditary and that healthcare professionals will be monitoring her daughter in the future.

Mary (first interview): ...I certainly felt concern, the fact because I'd had cancer that I was then influencing our children's chances of having it, and that's a horrible thing to feel you're passing on potentially bad genes or whatever.

Not planning for the future

Three of the four gynaecological cancer participants said that they do not plan for the future, but the reasons for this differ. Sue is pessimistic by nature. She feels that the future is not going to be as long as she once thought. In effect, she feels her life expectancy has been reduced as a result of her cancer diagnosis. Mary does not plan ahead because she wants to value the moment. This attitude is historical, borne prior to her cancer diagnosis, when some family friends were killed in an accident. However, it could also be associated with Mary's perception that she is living on '*borrowed time*.' She said it does not affect the way she lives day-to-day, but she may be valuing the moment because she is unsure about the future.

Claire (follow-up interview): ...I think, if anything, it's made me a better person because before this I would plan everything out, know what I was doing, I am still Miss OCD but not to that point. And now, I'm like "God you don't know what's around the corner so let's not worry about that, and let's not plan that far ahead because you just don't know". That's probably the only way now it's changed my life, or affected my life.

Other health conditions are of more concern than cancer

As already discussed, some participants experience a loss of certainty about their health, which is associated with not having any symptoms when they were initially diagnosed. As a result, when they are ill they fear it could be a recurrence. However, several participants feel that other health conditions are likely to have more of an impact on them in the future than cancer. Malcolm was diagnosed with diabetes after his cancer diagnosis and feels that diabetes, and its corresponding health risks, such as heart problems and stroke, are more likely to have an impact on his future health than cancer. In fact, he does not think that cancer (the disease at least) will have any impact on his future. Patricia is more concerned about

maintaining her mobility than cancer. She was relieved when she was diagnosed, and feels that she has had her 'turn.' She has had operations on both knees and has osteoporosis, which prevent her from engaging in certain activities, such as swimming and gardening. She is concerned that these conditions will prevent her from engaging in an active social life in the future.

EB (first interview): And do you think about the risk of recurrence?

Malcolm: My chances of recurrence, because after I was diagnosed with the cancer, I was also diagnosed later on with Type II diabetes, so my chances of having a stroke or a coronary are higher than having a recurrence of cancer.

EB: So there are other health conditions that are at the forefront of your mind?

Malcolm: No, not at the forefront of my mind, but they are logically, you know, those risks are higher.

Ageing is more of a concern than cancer

Linked to the discussion above, growing older, its associated health problems and an ability to remain active, were of concern to Roger, Margaret, Angela and Sue. Roger said that frankly, as a man in his mid-70s, his future is limited and that he has already outlived his biblical '*three score years and ten*'. However, he hopes that he has another ten years in him and that he will die of old age rather than anything else. Margaret is worried about developing dementia but she is also concerned about ageing and how her body will react. She hopes to remain flexible and mobile. To manage the uncertainty inherent in getting older, Margaret tries to live a healthy and active life. Angela is also concerned about ageing, particularly the impact bone-thinning might have on her ability to maintain her independent, active lifestyle. She is aware that her children may have to look after her in the future, so she wishes they would not worry so much about her now. Finally, Sue talked about how she does not want to live life in pain or discomfort when she gets older. She also

mentioned that she feels that as she gets older, she will have to limit the amount of walking she does, which is a popular pastime for her family.

Margaret (first interview): I mean now I am, and it's more conscious because of stroke and being slightly overweight and things like that, and finding that my joints are beginning to get painful and you think "oh god old age"... I think "oh don't want to get old". And then you think no Margaret, it's just because things are changing in your body, you need some more exercise, you need to do this, take a few vitamins, you know.

Lingering uncertainty from the perspective of 'significant others'

A sense of lingering uncertainty was also evident in the majority of the 'significant other' accounts. George mentioned that the future was much more uncertain in the aftermath of cancer: *'it's an anxious and uncertain time, but overtime these feelings lessen'*. However, some 'significant others' suggested that the sense of uncertainty was still strong and present in the lives of those close to them. As reported by participants diagnosed with cancer, the main manifestation of lingering uncertainty described by 'significant others' was fear of recurrence. Sheila said that cancer was not over for her husband as *'it obviously stays in his head'* and he is *'always frightened it's going to come back'*. In contrast, Geoff suggested that cancer recurrence was a *'very real possibility'* for both of them, but as long as they remain vigilant, fear of recurrence is not something that affects their lives all the time. Likewise, Lucy mentioned that *'there's always going to be that horrible niggle in the back of your mind that it might come back'*. For a couple of 'significant others' who have loved ones still involved in the cancer 'world', they too described how those individuals are reminded that cancer could come back. Peter and Penny said that their loved ones hear stories of people who have experienced a recurrence, or died. Peter therefore concluded that recurrence was a *'present possibility'* compounded by the fact that people who have finished treatment are said to be *'in remission rather than healed'*. These examples demonstrate the different levels of

uncertainty perceived by 'significant others' regarding fear of recurrence, ranging from a strong fear to a general acknowledgement that cancer could return.

Other manifestations of uncertainty include uncertainty about future health. Linked to getting older, Geoff said that he and his wife live with a sense that both of them could be affected by ill health. They deal with this uncertainty through not being complacent; always seeking medical advice if they are concerned. Peter said that his wife is pessimistic about her future health, questioning whether some of the aches and pains she experiences are due to getting older or linked to cancer and its treatment.

Uncertainty was also evident with respect to whether the side effects of treatment will continue. Sheila is concerned about how long her husband can keep fighting for, trying to overcome the side effects he experiences. She also wonders whether there will be a time in the future when they will be able to get back some semblance of the life they had prior to cancer. In contrast, Peter queries whether his wife will be able to carry on with certain activities that she loves, such as walking. Penny also touched on the ongoing discussions her friend has about whether she should have reconstructive surgery. They have been having such conversations for many years, and Penny feels they will continue to do so.

Finally, Peter touched on the uncertainty his wife feels about planning ahead. She does not like to make plans for fear that something will happen to prevent those plans materialising – *'she will always foresee the worst happening and I think she, cos she hears and encounters the slice of life where the worst has happened, it does darken her view of things really.'*

The place of cancer in long-term cancer survivorship

The analysis subsequently led me to consider the place of cancer in the lives of participants, in terms of whether it is in their past, present or future (the continuity dimension of Clandinin and Connelly's (2000) three-dimensional narrative inquiry space), or indeed in the foreground or background of their lives (Frank 1995). Evidence from this study suggests that the place of cancer in long-term survivorship is not static or fixed. It can oscillate between the foreground and background. All participants described events or episodes that remind them they were diagnosed with cancer and what they have been through. It is these '*reality checks*' (as Mary called them) that initiate this oscillation, as do, in some cases, other life events. Whilst several participants felt that cancer was generally at the back of their mind, i.e. they did not dwell on it, or it did not prey on their mind, certain reminders would bring cancer to the foreground. For others, cancer is always at the forefront of their mind, for reasons including an ongoing fear of recurrence, constantly checking for symptoms, and managing the consequences of treatment. The '*reality checks*' that temporarily pull cancer into the present, or perpetuate its place in the present, are presented below (Figure 9.3).

'Reality checks': reminders of cancer

Figure 9.3: 'Reality checks' experienced by participants

'Reality check'	Cancer or life event	Frequency 'reality check' is experienced
Pain/symptoms	Cancer	Ongoing/intermittent
Consequences of cancer treatment	Cancer	Ongoing/intermittent
Follow-up appointments/screening	Cancer	Intermittent
Meeting/talking to other people with cancer	Cancer	Ongoing/intermittent
Reading or watching stories about cancer	Cancer	Intermittent
Illness	Life	Intermittent
Low/anxious points in life	Life	Intermittent

Pain/symptoms

About half of the participants in the study described how experiencing a pain or symptom in the area where they had cancer, or were treated, makes them think about the possibility of recurrence. How much they worry is, in part, dependent on whether the pain or symptom persists. The majority who mentioned it knew that if the pain/symptom lasted for two or three weeks, they should consult a healthcare professional. A minority also wonder whether pain is a symptom of metastatic disease. For example, Richard, who was diagnosed with prostate cancer, mentioned that if he gets a pain near to where he received treatment, his first thought is that the cancer has spread to his spine, which he acknowledged *'is rubbish, it hadn't, you know it was back pain and it went away but that's the kind of thinking, perverse thinking, that you get when you're constantly worried that it's going to pop up somewhere else.'*

Malcolm (first interview): I don't dwell on it, most of the time, just occasionally, there is always that little nag that you get an ache or a pain. That will never go away because you always know that there is a slight risk of... but it certainly doesn't pray on my mind.

Consequences of cancer treatment

The consequences of cancer treatment, such as bowel and bladder problems, serve as a reminder of cancer to around half of the participants in the study. For some, the consequences of cancer serve as a constant reminder (Janet, Richard, Kate). For others, they are reminded from time-to-time (Malcolm, Roger, Angela, Moira).

Kate (follow-up interview): Apart from the bladder legacy, which terrifies me and makes me think about cancer, about blood, I would say I do think about it every day because I'm constantly looking at my urine and thinking "is it pink?"

Malcolm (first interview): ...[cancer] was something I had, it was something I was treated for, there are some long-standing side effects, most of the time they're copable with, therefore you ignore them, cos they're not interfering with day-to-day life. Occasionally they do.

Follow-up appointments/screening

Follow-up appointments and cancer screening serve as a reminder to some participants that they had been diagnosed with cancer. When a follow-up appointment is coming up, Claire said *'that's when, all of a sudden, you remember "God yeah I had cancer"'*. She went on to say: *'Just probably leading up to an appointment, you get a little bit "oh God here we go again", back to there...'* Going for a mammogram, Margaret said: *'I suppose there's a bit of anxiety... there was always that bit at the back of your mind...'* Linked to the fact that Moira did not have any symptoms, she feels nervous before follow-up appointments *'because, of the very nature of that kind of cancer, that you don't feel ill. So you can be perfectly alright and then you get this diagnosis.'* However, once she has been, she is reassured.

Conversely, Janet and Angela do not look at follow-up appointments as a means of checking for recurrence, as most participants in the study described, but a way of reaffirming that the cancer has still gone. Angela still has yearly follow-up appointments, but feels this has had a positive effect on her, partly because doctors are *'saying "you're fine, go away, we don't need to see you for a year." That's fine by me'* but also the ongoing appointments reassure her because *'they just keep an eye on you.'*

EB (follow-up interview): Actually, linked to, I had a question about when you go for your CT scans or colonoscopies, I was just wondering how you feel when you know you're approaching that time and have to go for that scan, and then how you feel when you're waiting for the results of it.

Janet: ...I think there's always a slight nervousness beforehand, when you get the appointment through, you know, thinking "wonder what this is going show up" but on the other hand, there's almost, I wouldn't call it excitement, that's not the right word, but it's almost a sense of anticipation, that "yes, it's another year" you know, "I've got this far" for instance, this year, I think I just have a CT scan which presumably will be around November time and I will think "great, that's 7 years" but yes, you then, with the CT scan you've then got to wait...

EB: I can only imagine, that sense of wanting to know.

Janet: That sense of doom (laughs). But [the oncologist] was brilliant about that, she used to get her secretary to ring up, in fact, she rang me herself once, cos the secretary was busy. But just getting that phone call, it's like a burden being lifted. And you think "yep, here we go, got another year."

Meeting/talking to other people with cancer

Meeting other people who have been diagnosed with cancer has positive and negative connotations for the participants in this study. They might meet other people affected by cancer in their day-to-day lives (for example, family, friends, etc.), during the course of their work, or if they are involved with cancer charities in some capacity. From a positive perspective, meeting other people affected by cancer serves to reassure participants, or give them a confidence boost, to say they have '*made it*' (Margaret, Patricia, Moira and Janet). The downside is that it can bring back memories of their own cancer experience, remind them that they are still a '*member of that club*' as Sue put it, serve as a reminder that the risk of recurrence is very real and generate feelings of survivor guilt.

Patricia said '*I find [attending cancer meetings is] nice because it keeps me in touch and it also makes me think I've survived, a lot of these people are just on their journey*'. She also mentioned that being involved with cancer charities is reassuring. Seeing other people who are just beginning their '*journey*' gives her the confidence to say that she has survived: '*when I first went to [a cancer charity] and I met people*

who were ten years down the line, it gave me confidence, as I now give other people confidence.' She reiterated this in the follow-up interview saying: *'It reassesses your confidence to sort of say "I've made it."*

Related to her job, Sue sometimes thinks *"oh it could have been me"* - and asks herself *"why am I ok?"* Sometimes patients will say something that will *'stir up memories'* for her. Equally, Sue sometimes still feels like a *'member of that club'*. When talking to people, something they say *'sort of hits me and I think "ooh I remember that"'*. Similarly, through her work with a breast cancer charity, Moira often meets women who are undergoing treatment and that triggers memories of her own experience, particularly if they are having chemotherapy, which she found distressing and debilitating.

Mary (follow-up interview): ...I mean that's been a reality check in so far as within the [patient experience] committee, we've currently got two members who've got a, rediagnosed with cancer and that's certainly been a reality check for me, and a real sadness for them.

Reading or watching stories about cancer

Some participants mentioned that if they read something in a newspaper or magazine, or see something about cancer on television, it triggers memories of their cancer diagnosis. Margaret reads obituaries in the newspaper and said she is always surprised by the number of people who have died from breast cancer *'and I'm thinking "bloody hell, that could have been me."*

Janet (first interview): ...if I hear on the television or read in a magazine or anything, or the newspaper, of somebody who's died of the cancer that I've had... I do find that it hits me and I feel low when I see that somebody has actually died.

Illness

Linked to experiencing pain/symptoms associated with cancer is illness more generally. Moira and Andy described that when they are ill, they wonder whether their illness is more than just a chest infection or sore throat, and that it could be cancer. When Moira is ill, she wonders *“oooh could it be something else.”* She refers to this as a legacy of having cancer, *‘so the minute something doesn’t go away as quickly as it should, you start thinking “oh I wonder what this is?” and I think people are a little more cautious after a diagnosis like that.’* Andy also mentioned that he worries if he becomes ill: *‘Even now, if I think, if there’s something wrong with me, I think “I’ve got it.” Even now.’* He recently had an ear infection and one of his glands was swollen: *‘and I thought “oh that’s one of them things in your neck.” What is it? Lymph nodes. Cos they used to check all round there and that, and if I find a lump, that’s it.’*

Also, as Moira did not have any symptoms when she was diagnosed, apart from tiredness, she experiences a nervousness about health:

Moira (follow-up interview): ...apart from this terrible feeling of tiredness I had, I can’t say that I felt anything at all that was any different. And that’s a slightly frightening thought, really to think that you can, and people do, develop cancer without really knowing that it’s there.

Therefore, it bothers Moira if she becomes overtired and cannot explain why. Andy mentioned similar feelings: *‘it doesn’t worry me now at all, really. As long as I feel alright. But then you can feel alright and still have it, can’t you?’*

When someone enquires about Claire’s health, it reminds her that she was diagnosed with cancer: *‘it’s only if someone would mention it to me, “oh how’s your health” or “how are you doing?” that then you go “oh God yeah, I had cancer didn’t*

I? Oh yeah, bloody hell, that was fun". I've worn the t-shirt.' As a result of these instances, cancer comes to the forefront of her mind.

Low/anxious points in life

Both Angela and Moira mentioned that they are sometimes reminded of cancer when they experience low or anxious points in their lives. For example, Angela said *'I suppose there are [triggers]. It might be just a quiet moment, something might crop up about my mum and I'll be saying "oh do you remember that time?"'*

Typology of the place of cancer in long-term cancer survivorship

The place of cancer not only oscillates between the foreground and background as a result of *'reality checks'* experienced by participants, but it also seems to shift between the past, present and future. Therefore, to describe the place of cancer in long-term survivorship, I have developed a typology, identifying sub-groups within the overall category *'place of cancer'*: cancer is in the *past*, *past-present* and *present-future*. In the following section I discuss the sub-groups in greater detail, outlining the key characteristics of the participants in each group, and exploring possible explanations as to why participants may fall into the groups identified.

Cancer in the 'past'

Figure 9.4: Cancer in the 'past' – key characteristics

Participants 'had' cancer – the disease has gone
Participants do not experience ongoing consequences of treatment that affect daily functioning
Survived cancer and survived the experience of cancer
Cancer is drawn into the present from time-to-time as a result of <i>'reality checks'</i>
Some identify with being a <i>'cancer survivor'</i> , whilst others do not
Awareness that cancer has the potential to affect the future, but fear of recurrence is low

For Patricia and Claire, cancer is in the past. They would describe themselves as having *had* cancer and they do not experience ongoing consequences of cancer treatment that affect daily living. Both are aware that cancer has the potential to affect the future, in terms of recurrence, but feel that if they were diagnosed again they would deal with it in the same way they did their original diagnosis. As such, their fear of recurrence is relatively low. Whilst cancer is predominantly in the past, triggers or '*reality checks*' can temporarily bring cancer into the present for these women.

Comparing and contrasting accounts

There are several differences between Patricia and Claire in terms of both their cancer experience and wider life context. They were diagnosed with different cancers (Patricia with breast cancer and Claire with cervical cancer), received different treatments, were diagnosed at different ages (Claire was diagnosed in her 30s whilst Patricia was in her 50s), and their time since treatment completion also varies (Claire was five years post-treatment whilst Patricia was nine years post-treatment at the time of interview). Their relationship, parenthood and employment status also differs. Claire is in a long-term relationship, with no children and works full-time, whereas Patricia is divorced, has adult children and is retired. Claire does not have any ongoing health problems, whereas Patricia has mobility issues as a result of osteoporosis and knee surgery. Patricia said that these health issues are of more concern to her than cancer.

Interestingly, whilst Patricia clearly defines herself as a cancer survivor, Claire said that even though she is a 'survivor' - because she literally survived a life-threatening illness - she would not use the label to describe herself to others. Patricia is reminded that she had cancer when she attends cancer meetings, but this can actually be a positive for her as meeting other women who have survived for many

years reassures her and gives her the confidence to say that she too is a survivor. In contrast, by comparing herself to others, Claire distances herself from the 'survivor' label. She mentioned young children she met during treatment, whom she perceives have been through much worse than herself. Neither Patricia nor Claire endorse the term 'living with cancer.' Patricia said: *'I don't feel I'm living with cancer. I feel it's behind me now.'*

However, Patricia and Claire are similar in their positive approach to managing the impact of cancer on their lives, and the benefits cancer has had on their sense of self and outlook on life. They appear to have optimistic personalities, but also come across as quite pragmatic. For example, they both feel that their chances of developing cancer again are now the same as the wider population, but if they were diagnosed again, they would deal with it in the same way. They both volunteer for cancer charities, helping to raise awareness about cancer and improve services. Claire feels she is even more positive than she was prior to diagnosis, but has slowed down and takes each day as it comes. Patricia feels stronger, that cancer has '*hardened*' her up and, as such, does not let people '*trample*' over her as they have done in the past.

Another way to try and understand the place of cancer is to look at the coping strategies adopted. Claire and Patricia both saw cancer as a challenge to overcome and shared similar problem and emotion-focused coping strategies to achieve this including: putting their faith in healthcare professionals, a positive, optimistic attitude, seeking peer support, social comparison, drawing on wider support networks of family and friends and humour. Time was another important factor for these women. Reaching the five-year survival point was key to enabling them to put cancer behind them. After treatment, Patricia said the five-year marker seemed a '*lifetime away*' but when it arrived she described it as a '*lovely feeling. I remember coming [home] that day and feeling so pleased... I came in elated... "I'm on top of the world. I've been discharged."*' It is telling that Patricia said '*my journey ended*

after five years.' It seems that once she was discharged from follow-up, and no longer taking Tamoxifen, she was able to put cancer behind her. Claire said that on reaching the five-year point, *'it's all sort of come to a bit of an end now'*. She has drawn a line under her cancer experience: *'it's been done, gone, and I've forgotten'*.

The five-year marker was clearly a turning point for these women. Cancer had consumed them both. Claire experienced post-traumatic distress disorder in the transition period, and Patricia had three attempts at reconstructive surgery before it was successful. However, they focused on the five-year point, with both mentioning the statistics associated with the milestone. Patricia talked about the number of cancer survivors alive today, and how that number is increasing, and that her risk of recurrence was greatest between two and five years, whilst Claire discussed how her chances of developing cancer again are the same as everyone else – quoting the *'1 in 3'* statistic. By reaching the five-year point, experiencing few, if any, side effects of treatment, along with their positive attitude and outlook on life, these two women have been able to put cancer behind them. Patricia described feeling *'elated'* at the five-year marker, whilst Claire said that reaching it was an *'extreme high'* and she felt that she could breathe again for the first time in five years.

Cancer in the 'past-present'

Figure 9.5: Cancer in the 'past-present' – key characteristics

Cancer (the disease) is in the past
<u>But</u> participants are living with physical consequences of cancer and its treatment that affect physical functioning, therefore cancer is also in the present
Survived cancer but continue to survive the experience of cancer
Cancer can affect physical functioning on an ongoing basis, or intermittently
Participants are not 'living with cancer' – the disease has gone
Some identify with being a 'cancer survivor', whilst others do not
Acknowledgement cancer may affect the future, with some experiencing a strong fear of recurrence

The biggest sub-group, with seven participants (Sue, Mary, Kate, Angela, Moira, Malcolm and Janet) included those for whom cancer *as a disease* is in the past, but they continue to live with the consequences of cancer and its treatment which affect physical functioning – some from time-to-time, others on a daily basis. Therefore, for these participants, cancer also remains very much in the present. These participants acknowledge that cancer might also affect their future, both in terms of recurrence, but also if the consequences of cancer and its treatment continue. As such, some of the participants in this group have a strong fear of recurrence. However, this group would *not* say they are ‘living with cancer’ as they perceive that the disease has gone - it is the consequences of cancer and its treatment that they have live with. As with the ‘past’ group, there are those who identify with being a ‘cancer survivor’ and those who do not.

Comparing and contrasting accounts

There are several differences between the participants in the ‘past-present’ group. They were diagnosed with different cancers (ovarian, cervical, breast and colorectal), differed in their time since treatment completion (six to sixteen years at the time of interview) and received different treatments. They were in their 40s and 50s when diagnosed and ranged from 50 to 65 years old at the time of the interviews. They also differed in terms of their gender (although the majority were women), employment status, relationship status and cancer charity involvement.

However, this group was similar in that cancer affects their physical functioning to some extent. Three participants experience ongoing side effects of treatment that affect them on a daily/regular basis. Sue experiences ‘*chemo-fever*’ which limits her daily activities. Indeed, she said she has to ‘*live within her boundaries*’ today. Kate checks for blood in her urine daily and described herself as ‘*hyper-vigilant*’. She also experiences sexual and relationship problems, and has to manage her diet to

prevent irregular bowel movements. Likewise, Janet checks for blood in her stools on a daily basis and manages her diet, to *'keep her regular'* and to try to prevent recurrence. Three participants experience ongoing side effects of treatment that affect them from time-to-time. Angela is affected by bone-thinning which can cause pain and may, in the future, prevent her from taking part in some of the physical activities she enjoys. Moira experiences body image concerns in the summer when wearing summer clothing and swimming costumes with a prosthesis. Malcolm said the side of effects of treatment, including impotence, irregular bowel movements, chemo-brain and peripheral neuropathy are an *'annoyance'* occasionally, but not a problem day-to-day.

The present place of cancer in Mary's life is slightly different to the six participants described above. She is involved with a cancer support group and patient experience group on an almost daily basis, to the point where she noted that she has the *'balance wrong'* in her life. Cancer plays too much a part in her life. She feels guilty doing other activities, such as hobbies, as she thinks she should be checking her emails, organising speakers, etc. In our first interview, Mary said *'I feel that I've had cancer, it's an illness, and I'm just lucky that I'm well. I think I call myself well, rather than a survivor'*. However, at the time of our follow-up interview Mary was also having investigations for a persistent pain in her stomach, which she was concerned was a symptom of recurrence. Here we can see how *'reality checks'* such as volunteering for cancer-related activities and pain/symptoms of recurrence can bring cancer into the present when, for the most part, cancer (the disease) is in the past.

These participants adopt various strategies to manage the physical and psychological consequences of cancer and its treatment, and the resultant place of cancer in their lives. As we might expect, several strategies are similar to those identified for the *'past'* group, as they all perceive cancer (the disease) to be in the past. All participants, apart from Malcolm, talked about the importance of support

networks. The majority also have a positive attitude and outlook on life. The main difference is that a common action for this group is adopting a healthy lifestyle. This group is distinct from the cancer in the 'past' group, as they are managing the consequences of cancer treatment and are generally more concerned about the risk of recurrence. As such, they employ more active, problem-focused strategies such as managing their diet to control side effects and/or manage the risk of recurrence. Another action common to the majority of this group is seeking information, for example, regarding signs and symptoms of recurrence and, as Janet put it, '*everyday information*' necessary to manage little '*niggles*' and side effects of treatment that can affect physical functioning.

Kate and Janet identify with being a 'cancer survivor', whilst Mary, Moira and Malcolm do not. Kate feels that the term 'survivor' is positive as it indicates that you have left cancer behind you and come through it. Janet said that she '*most definitely*' identifies with the term as it conveys that cancer is not a death sentence and that there is life after a cancer diagnosis. In contrast, Mary '*hates*' the term 'survivor'. To her, she had an illness, it was treated and now she is '*well*.' Like Mary, Malcolm views cancer as a disease that was treated and he does not have it any more. Moira also used the term '*well*' to describe herself. She said that, whilst she may be a survivor, day-to-day she does not identify with being one. Sue and Angela were ambivalent about the term. Sue said 'survivor' implied she had done something to make her a survivor when actually she had not done any more than anyone else. Angela said that whilst she may be a survivor, she does not see herself that way and would not want people to think she portrays herself as such. Those with more serious cancers, or recurrence, are survivors in her eyes.

Experiencing the ongoing consequences of cancer means cancer is in the present for these participants – they continue to survive the experience of cancer. However, none of them agree with the term 'living with cancer'. These seven participants

tend to think that 'living with cancer' refers to those going through diagnosis and treatment, or those who are living with a cancer that cannot be cured.

I wanted to explore how these participants were able to put cancer (the disease) in the past (they survived cancer – the disease) when they experience the ongoing consequences of cancer treatment, alongside other '*reality checks*', that result in cancer's fluctuating place in the present (they continue to survive the experience of cancer). A starting point was participants' perception of the cause of their cancer. I wondered whether knowing the cause of their cancer would help them put the illness episode in the past, as they might then be able to take steps to prevent it coming back thus reducing their fear of recurrence. All participants in this group are aware that cancer has the potential to affect their futures. Some stated that they have a fear of recurrence (Mary, Kate and Janet) whilst others are aware of the possibility but it does not worry them, or they do not dwell on it (Sue, Angela, Moira and Malcolm). Janet feels nervous about recurrence because she does not know why she developed cancer and therefore does not know what to do to prevent it returning. Mary also feels nervous because there was no immediate reason why she should develop cancer and does not know what signs or symptoms to look out with regards to possible recurrence. Only Malcolm and Kate have formulated a reason for their diagnosis. Malcolm attributed colorectal cancer to his diet and Kate felt HPV was the causal factor in her cervical cancer diagnosis. Interestingly, whilst Malcolm does not think cancer will affect his future, Kate has an ongoing, yet oscillating, fear of recurrence. Indeed, her narrative is one of fear, despite formulating a reason for her diagnosis. Therefore, for this group, there did not seem to be a clear relationship between knowing the cause (or not) of their cancer, fear of recurrence and putting the disease in the past.

It appears that the passage of time has helped four of the seven participants in this group to put cancer in the past. For example, Kate said that her fear of recurrence has receded over time and that '*time does its usual healing thing*' and Angela said

that *'as time goes on, you feel much more relaxed knowing it's all passed...'* Again, I think the importance of the five-year/ten-year marker should be highlighted as a factor enabling participants to put the disease behind them.

As for the cancer in the 'past' group, the five-year marker served as a means of drawing a line under the cancer experience, giving them the confidence to say they had survived that illness episode, either because healthcare professionals had emphasised reaching that point, or participants were aware of the survival statistics. It was a key *'milestone'* for Mary and a *'turning point'* for Janet. Reaching five years of survival allowed Mary to say *'now I can move forward.'* With each annual follow-up appointment, Janet said it was another year *'ticked off'* and it gave her the confidence to think she would continue to survive. When she was discharged, she said healthcare professionals gave the impression that they were confident the cancer had gone. Janet said: *'I went out and had a decent meal and nice bottle of wine (laughs). It was, it was definitely a celebration. It was a really positive feeling...'* Kate said that cancer had controlled her life up to the five-year point and that *'officially'* she was likely to be ok after that point. It seems that it was a point that helped Kate move on: *'Up until probably five years, it absolutely controlled my life. Totally. Totally overshadowed it and totally controlled my life.'*

Angela celebrated with friends at the five-year point and used words such as *'lovely'* and *'brilliant'* to describe how she felt at that time. She said at five years she felt like *'that was the end of that'* particularly because she could stop taking Arimidex, which had caused her distressing menopausal symptoms that impacted her ability to work effectively. Angela still has ongoing, yearly follow-up appointments but they are reassuring as she feels that healthcare professionals *'keep an eye on'* her. She also feels she can get back into the NHS system if she needs to.

In contrast, Moira was left confused by the significance of the five-year marker, feeling that its importance is *'pushed into'* those diagnosed with cancer, whether it

be when filling in insurance forms or reading about breast cancer. She wondered whether it meant she was expected to live much longer, or had been expected to die before the five years.

Interestingly, Malcolm was the only participant who felt that no emphasis was placed on the five-year point. This could be linked to the fact that he moved shortly before reaching this point, changing hospital and GP, so he felt '*cut off*' and as if he had been '*thrown out*' of the system. He said he was not told he was cured or in remission but still feels that cancer was successfully treated and will not affect his future. Sue, being fourteen years post-treatment, did not talk specifically about the five-year marker, or indeed a ten-year marker. She made the decision to stop attending follow-up appointments because she felt guilty going to clinic and seeing ill women, when she was ok. I think for Sue, the '*rational knowledge*' of ovarian cancer she receives through her job, has helped her put her illness episode in the past, although it obviously comes to the foreground when she speaks to women diagnosed with the disease.

Cancer in the 'present-future'

Figure 9.6: Cancer in the 'present-future' – key characteristics

Cancer (the disease) is in the present
Participants are living with cancer <i>within</i> them - the disease has not gone; they are not cured
Participants may also be living with the physical consequences of cancer and its treatment which affect physical functioning on an ongoing or intermittent basis
Some identify with being a 'cancer survivor', whilst others do not (<i>survived</i> cancer and the experience vs. <i>surviving</i> cancer and the experience)
Participants feel cancer and its consequences are likely to affect the future, but a strong fear of recurrence is not universal

The final group includes participants for whom cancer is in the present. Whilst they are currently disease-free, these participants feel they are living with cancer *within* them - using words like '*brewing*', '*dormant*' and '*remnants*' to describe cancer and

its place in their lives. Four participants fall into this group: Roger, Richard, Margaret and Andy. In addition, the two prostate cancer participants, Roger and Richard, are living with the consequences of cancer treatment that impact their physical functioning and relationships today, and potentially in the future. Roger experiences erectile dysfunction as a result of a prostatectomy and Richard has urological problems after radiotherapy. As a result, Richard describes cancer as the *'focal point'* of his life. Therefore, for these four participants, cancer (the disease) has *not* gone. Cancer is very much in the present, and they feel that both the disease and its consequences have the potential to disrupt the future.

Comparing and contrasting accounts

The four participants in the 'present-future' group are different in many respects. In terms of cancer-related characteristics, they were diagnosed with various types of cancer (prostate, breast and testicular), differed in their time since treatment completion (five to sixteen years, although three were over ten years post-treatment) and they received different treatments. Regarding the socio-demographic characteristics of the 'present-future' group, the age range was broad (late 20s to early 60s at diagnosis, and mid-40s to mid-70s at the time of the interviews), and some participants have children, whilst others do not. Three of the participants in this group were men.

Cancer is in the present for this group, in part, as a result of their perception of cancer as a disease, and its causes. This group is similar in that they do not believe they are free of cancer - the disease has not gone. Roger feels there could be *'remnants'* of cancer in his body and would not say that he is cured. Richard feels he is living with cancer and will never be free of it. He mentioned that he is free of cancer at the moment, but cannot say he will always be free of the disease. Margaret admitted that there could still be cells in her body, lying *'dormant'* and Andy feels that cancer floats around your body, settles somewhere and grows.

Andy (first interview): I don't think it ever goes away for anybody. I don't think you'll ever, that's it, once you've had that, it will never go away. You just have to learn to deal with it.

All participants in this group, apart from Roger, are concerned cancer could come back somewhere else. Andy said that when he was recently ill with a sore neck, he thought he might have a tumour in the lymph nodes. Margaret is more concerned about developing colorectal cancer in the future, particularly as she feels it is a more serious cancer than breast cancer. Richard mentioned that he worried at one point that he may develop cancer in the spine, as it is so close to the prostate. In contrast, Roger seems primarily concerned about the risk of prostate cancer recurrence. After recent knee surgery, he requested a PSA test to check whether problems he experienced with catheterisation during surgery were due to scar tissue or a recurrence.

In terms of survivorship discourse, the individuals in this group appear to identify with the term 'survivorship', but in a different sense to those in the 'past' and 'past-present' groups. It seems Roger and Richard are *surviving* cancer - they have not survived. As Richard said, he is free of cancer – at the moment. Roger said he does not use the term 'survivor' as he feels it assumes 'cure'. Both men are also surviving the experience of cancer, living with the consequences of treatment and the impact they have on physical and sexual functioning. Margaret and Andy feel they have survived the specific illness episode (breast cancer in Margaret's case and testicular cancer in Andy's case), but cancer is still *within* them and has the potential to develop somewhere else. Margaret mentioned that she does understand why the term 'survivor' is used but would not wear it as a '*badge*' or way of identifying herself.

It is interesting to note that both men with prostate cancer fall into the 'present-future' group. These men volunteer for the same cancer charity, and both mentioned that the organisation is careful not to use the word 'cured'. Involvement

with this particular charity may have influenced how they perceive cancer, and the place it has in their lives. Also, Andy was the only participant in the study to be told by healthcare professionals that he was cured, yet this has not allayed his fears about cancer, death and dying. Whilst he feels the specific episode of testicular cancer is over, cancer is still within him, and he feels it will ultimately '*rear its head*' again. It is also interesting that three of the four participants in this group were diagnosed over ten years ago (Margaret, Andy and Roger). I wonder whether their perception of cancer is borne out of wider society's perception of cancer at the time of their diagnoses. The perception of cancer, as well as treatments and survival rates, has changed a great deal in that time. It is possible that when they were diagnosed, the pervading view of cancer was still that of a death sentence, and that once diagnosed, the disease would always be within you. However, it is interesting to compare these views with those widely reported today. Breast, prostate and testicular cancer have amongst the highest survival rates of all cancers, which makes it all the more fascinating that these four participants fall into the 'present-future' group.

The 'present-future' group adopt a range of emotion and problem-focused coping strategies, but only one strategy was described by all four participants – acceptance. The majority draw on support networks (particularly their partners) and, like the 'past-present' group, most try to adopt healthy lifestyle practices. I speculate that they engage in these activities to manage the risk and fear of recurrence. For example, Richard has changed his diet and Margaret manages her stress levels to reduce the risk of recurrence, as although they cannot be sure, they suspect that diet and stress respectively were the reasons for their diagnoses. Whilst Andy feels cancer will come back, he believes those who are healthy have a better chance of getting through cancer. As a result, he is trying to lead a healthier lifestyle.

As mentioned, the four participants in the 'present-future' group talked about how they have accepted their cancer diagnoses and, it seems, the present (and potentially future) place of cancer in their lives. Roger and Andy said cancer is just one of those things that happens. Roger accepts that as he is in his 70s, cancer might just have been something that happened to him because of his age, whilst Andy feels that cancer is the disease that runs in his family. It seems Andy has accepted that fear of recurrence will never disappear, nor will the possibility that he will develop cancer again. As a result, he has tried to '*learn to deal*' with this uncertainty. Richard, having questioned 'why me?', now accepts that he will never know why he was diagnosed, has come to terms with what has happened to him and feels he manages his ongoing problems well. Once Margaret knew more about her cancer diagnosis, she was able to accept what had happened to her. I think this stemmed from her need to be in control. It seems that once she knew the specifics of her cancer diagnosis she felt more in control and subsequently able to accept her diagnosis.

This group are also similar in that they are managing, or worrying about, other health conditions. Roger has mobility issues after knee surgery and circulatory problems; Richard has a heart condition, which restricts his mobility and means that he is prone to blackouts; Margaret is worried about developing dementia or having a stroke, as these conditions are common in her family; and Andy has struggled with alcohol abuse. These individuals may be worrying about their health more broadly, which perpetuates cancer's place in the present. Equally though, living with cancer amongst other health conditions may have helped these participants accept what has happened to them. This is not to say that individuals in the other sub-groups do not live with additional health concerns, as they do. For example, Patricia has knee problems and osteoporosis and Malcolm has diabetes. The difference is that in the 'past' and 'past-present' groups, other health conditions are of more concern. In the 'present-future' group, cancer is still of primary concern.

The five/ten-year marker seems to have different connotations for the 'present-future' group. Rather than being positive, reaching this point was quite unsettling for Roger and Andy. Andy felt that his *'security blanket'* had been taken away, and that if he was not being monitored, something might be *'brewing'*. Whilst Roger said it was a positive, he questioned *'are they right?'* – and that uncertainty has continued (as evidenced by his recent request for a PSA test). Richard was also pleased to reach the five-year marker but he said it was only a *'theoretical marker'* and was well aware that people can still experience a recurrence after that time. Margaret, who finished treatment sixteen years prior to the study, could vaguely recall aiming for five years: *'in your head, you're saying "five years" – and that you are aiming for that point, because that is the way healthcare professionals look at it.'* However, she went on to say that eventually she missed a follow-up appointment and *'just stopped going. I mean you could carry on but I just stopped going in the end.'*

The place of cancer from the perspective of 'significant others'

The place of cancer in the lives of those who have been diagnosed with cancer and their 'significant others' appears to be guided by several factors including whether the person diagnosed has ongoing involvement with cancer charities, but also the perceived risk and fear of recurrence, triggers that remind individuals they were diagnosed with cancer and the ongoing consequences of treatment. As such, whilst cancer may be in the past for the 'significant other', or they wish it to be in the past, some are aware that it is still in the present for the person diagnosed and there is a need to remain vigilant for signs and symptoms of recurrence. Interestingly though, a few 'significant others' perceive that their loved ones do not think much about cancer today, whereas those diagnosed have actually said it is a constant at the back of their mind.

Peter suggested that the prominent place of cancer in their lives is *'skewed by the fact that [his wife's] job is also to advise and support and be there for others'*. He wants to put cancer in the past but feels that it is always in the present for his wife. He said *'whereas I tend to think "oh she is fine, she's over it now" I think [she] will live with a "no, I'm not over it cos I do talk to people on the phone who it comes back or in a different way or whatever" whereas I'm not so aware of that'*. He does not find it helpful reminding himself, or making a big thing of it, but it is at the back of his mind.

George commented on how busy his wife is with cancer groups, and speculated that she might forget about cancer if she was not so heavily involved. George thinks his wife only thinks about her cancer experience *'from time to time.'* For example, he mentioned how his wife will *'occasionally have a pain or something or other, wondered if it was a subsequent side effect or, I suppose those sort of things crop up from time to time which wouldn't have done otherwise'*. He said that his wife felt a sense of relief at the five-year marker. However, he feels that his wife now spends more time in the present than she does thinking about the future.

Sheila feels her husband was unfortunate to be diagnosed at a relatively young age. She said that for him, the end of treatment did not signal the end of cancer: *'I haven't got it but I should imagine, you know, you do, you get very "is it coming back?'* This, coupled with the ongoing consequences of treatment her husband experiences, cancer is very much a constant in their lives today.

Geoff mentioned that when they hear of friends or colleagues who have *'succumbed'* there is a *'small replay'* of his wife's experience. He went on to say that cancer is not like mumps *'once you've got that, it's not going to come back because you've got immune to it.'* Therefore, they are not complacent, acknowledging that cancer could come back. As a result they are vigilant for signs and symptoms of recurrence, and do not hesitate to consult their GP if concerned. This being said, he

did not feel his wife was living with a fear of recurrence but they both know that it is a *'very real possibility.'*

Geoff: Well I certainly, every now and then, I've got to not get complacent about it. There is the view that we've cracked with one, lucky to get away this time, but you know, you hear of so many people where it's come back after a number of years. So I certainly feel that we've been extremely fortunate, well I wouldn't say this is borrowed time but, you know, it might come back.

They are cognizant of the fact that either of them could be touched by cancer, but equally mindful that they could be diagnosed with another illness associated with ageing. Geoff said that although it was clearly a difficult time for his wife, *'it wasn't as bad as it could have been.'* Despite this, he said *'it isn't something you go through and come away unscathed. It's part of you... it's something that's internalised now...it's something you absorb into your way of life in a sense.'* Therefore, when asked what place he felt cancer had in his wife's life today, Geoff said that he did not think his wife thought out it every day.

When asked what place Amy thought cancer had in her mother's life, she felt it was in the past:

Amy: I don't think it has [a place in her life] anymore. I really don't think she thinks about it too much... now I could be completely wrong (laughs) you know, I'm thinking "does she?" No, I don't... I think it's something she's had, she's dealt with and she doesn't worry about it, harbour it, I think she just thinks "been there, done that, got rid of it, gone."

Amy said their family do not worry about their mother today. The family went through a difficult time but it is now in the past. Amy went on to say: *'I've sort of blocked it out a little bit really'*. It could be that they do not worry about their mother because they are guided by her positive approach to cancer.

EB: And what about you and the rest of your family, do you still think about it?

Amy: Not really cos mum really doesn't mention it. You know, whenever she goes for a breast check, I'm like "everything ok? Yeah? That's brilliant." When she had her surgery earlier on this year, that was a little bit of a worry but she came out of that absolutely fine. No, I see it as it was a bit of a bad time, got through it and life's good. I don't worry about it... I don't worry about her and I don't worry that it's going to come back or "my god it's hanging over me like a big black cloud." Hanging over the family like a big black cloud. I think because we were lucky. I think we dealt with it, it went and we got on with our lives. Other people haven't had that luck, you know, that nicer story, I suppose, nicer ending, you know?

Penny wonders, in reference to her friend volunteering for a cancer charity, whether there comes a point when *'you just need to take a step back... I think after a while, you know, there's only, you can give so much back to breast cancer, but perhaps there's another avenue that you can help... sometimes maybe there's a fatigue.'* It seems that Penny may think the ongoing volunteering prevents her friend from moving forward with her life, and that whilst she wanted, and needed, to give something back after her diagnosis, now was the time to pursue other interests. Penny is also concerned that worries about recurrence are triggered by her friend's encounters with other women with breast cancer:

Penny: But the problem of actually having a lot of support with people with breast cancer is that sometimes the ladies don't survive. And although people can be very realistic, it's very painful to see somebody that you're working alongside actually, you know, develop cancer again and maybe not survive this one.

Penny also said that when her friend experiences an ache or pain, *'there is more a thought of could this be a cancer than perhaps anybody who hasn't had cancer would think.'* Penny said that the five-year marker was a great time as it provided a sense of relief: *'Every year seemed to be a gift, but now it's so many years on now that it's not mentioned.'*

When I asked Lucy how significant the five-year point was for her mother, she described it as a real '*turning point*' and a relief for everybody as they believed the risk of recurrence was now reduced, and she did not have to have as many tests and scans. However, Lucy mentioned that the ongoing CT scans are reassuring for her mother:

Lucy: I think [five years] was very significant. I think, as I say, we always knew they'd caught it early and the prognosis was good, but to have that final, not final, but you know, it had been five years and everything was still fine, you're going down to less scans and tests and stuff, there's always a relief as I think that's the huge sort of turning point in the, I don't know what the statistics are, but I think the chances of it coming back are much reduced. I think it was a huge relief definitely, for everybody.

Lucy: ...she's been all clear for more than 5 years now, so she's down to a reduced amount of tests every now and again, just to make sure it's still gone.

The above quotes suggest that Lucy feels her mother's cancer has gone, and the ongoing tests serve not as means of checking whether the cancer has come back, but to reassure them all that it has still gone. As follow-up appointments and tests are not as frequent and her mother has been '*all clear*' for more than five years, Lucy said '*she probably doesn't think about it as much because there's longer between having to go for scans and things like that... I think she probably goes without thinking about it for longer periods. But on a day-to-day basis, I don't know that she would worry about it too much.*'

Lucy: I don't know that it has a big place in her life. She doesn't talk about it too much. I know that she obviously helps out with a cancer charity so she's, you know, she's trying to use her experiences to obviously help other people that are going through similar things.

Contrasting accounts of the cancer experience from those diagnosed and their 'significant others'

In the following section I present findings from the dyadic analysis, where I compared and contrasted the accounts of those diagnosed and their 'significant others'. The following discussion focuses on contrasting elements of the accounts and is presented at the aggregate level, without pseudonyms, to protect the anonymity of those in the study. Contrasts in the accounts of the cancer experience discussed by participants and their 'significant others' centre on the impact of restricted lifestyles, communication and interaction, the extent to which the individuals diagnosed continue to seek an explanation for their diagnosis and the perceived place of cancer in the lives of those diagnosed ('past' vs. 'present'; foreground vs. background).

The impact of restricted lifestyles

The most contentious issue for one couple has been how restrictive the consequences of cancer have been on both their lives. One wife in the study feels she has to do things on her own now because her husband is not fit enough to do them with her. In addition, this wife would like to travel abroad but her husband finds this difficult. She finds this frustrating, but understands that her husband does not want to be away from the '*safety net*' of the local hospital, should he have a problem. Therefore, they both now lead a more restricted life as a result of her husband's diagnosis, one that she hopes will become less restrictive in the future. Whilst the wife is frustrated by the limits placed on her life, her husband is actually happy and content with the boundaries now in force, as it means he can focus on the things he really enjoys, including his family.

Communication between loved ones

One daughter suggested that her mother told her more about her cancer and feelings than she did her sons because her mother would not want to worry them. Yet, the mother said that she did not hold anything back from her sons, and did not treat them any differently. In fact, it appeared from the mother's account that she was more worried about her daughter's reaction to her diagnosis, describing her daughter as being *'in a state'* when she was diagnosed. It is therefore possible that the mother actually did not tell her daughter certain things, or put on a brave face, to protect her daughter. The daughter did acknowledge that her mother probably put on a façade at times and played down the bad times, saying *'I imagine she would have had some quite bad times and just then put on a smiley face and gone "oh yeah, yeah, yeah I'm alright"'*. However, she also said that her mum *'is very open with me, she tells me how she feels.'* So, the daughter is aware that her mother might not always have confided in her, but for the most part thought her mother would share how she was feeling. There was a sense in the mother's narrative that she wanted to protect her children, but equally the daughter said that when her mother was diagnosed she who went into *"mother"* mode and felt very protective, *'probably being a bit over-protective'* of her mother. From our discussions, the mother might not have needed that from her daughter, as she was an independent woman, who had been looking after herself for some time and did not perceive cancer as life-threatening.

Contrasting perceptions of seeking an explanation for cancer

One daughter did not think her mother had spent much time looking for an explanation as to why she developed bowel cancer. However, her mother clearly has, and is frustrated that she does not know what caused her cancer because it means she cannot take preventative steps to stop it coming back. Her daughter said her mother accepted the diagnosis and just wanted to get on with treatment.

Whilst true, her mother actually talked at length about risk factors for cancer and her frustration at not being able to take positive steps to prevent recurrence.

Contrasting accounts of the place of cancer

One mother alluded to the fact that she thought her children had trouble forgetting that she had cancer, whereas she has moved on. Interestingly though, her daughter said that she does not worry about her mother or the cancer coming back, because her mother does not mention it. To her, cancer was not *'hanging over the family like a big black cloud.'*

Another daughter in the study perceives cancer to be in the past and that her mother does not worry about it much on a day-to-day basis. However, it is, in fact, still a big part of her mother's life, as she worries about recurrence and what she might miss if she were diagnosed with cancer again. Her daughter did acknowledge, just as her mother did, that *'there's always going to be that horrible niggle in the back of your mind that it might come back.'* She said that her mother does not talk about cancer much anymore. Whilst this may be the case, this does not mean her mother does not think about it. In fact, her mother said that cancer is in the back of her mind all the time. She always checks for blood after she has been to the toilet, referring to that as a *'daily habit'*. Explanations for this contrast could centre on the fact that individuals living long-term after a cancer diagnosis may not want to talk about cancer anymore; they want to put it behind them and get on with living. However, the *'cancer fatigue'* argument put forward by Malcolm could also be at play – after a while even loved ones may not want to listen to individuals talking about cancer. Individuals living long-term after a cancer diagnosis are often aware of this and therefore do not always share their fears and concerns.

Discussion: understanding the experience of long-term cancer survivorship

Benefits and losses during long-term cancer survivorship

All thirteen participants said that something good had come out of the cancer experience, but this was to varying extents. However, whilst they all described 'something good', Kate said that she would rather still be a '*crap*' person than go through the cancer experience. This sentiment echoes findings from McGrath's (2004b) study, which reported that long-term haematological cancer survivors 'in spite of positives, could have done without the experience' (2004b: 235). In the wider chronic illness literature, Lau and van Neikerk (2011) found that young burns survivors described 'unexpected gains' which resulted in what they referred to as a 'bitter-sweet' experience.

Findings from this study support the notion that positive and negative impacts of cancer co-exist. Facets of post-traumatic growth - changes to self, relationships and philosophy of life (Tedeschi and Calhoun 1995) - are evident in the narratives presented in this study, but these positive changes are often accompanied by simultaneous losses. Previous research has shown that long-term cancer survivors can experience positive growth after a cancer diagnosis, whilst simultaneously experiencing losses or 'fallout' as a result of the disease and its consequences (Pelusi 1997, Tomich *et al.* 2005, Bertero and Wilmoth 2007, Doyle 2008, Sekse *et al.* 2009, Helgeson 2010, Kahana *et al.* 2011, Schroevers *et al.* 2011). As such, findings from this study support Kahana *et al.*'s (2011) notion of post-traumatic *transformation*, a concept used to encompass the duality of positive and negative experiences. However, what this study highlights is the variable extent of this transformation and a need to explore the duality of positive and negative transformations that seem to occur during the long-term survivorship phase. Psychosocial oncology research needs to move away from focusing on the

extremes, as has been the case until relatively recently. As the cancer narratives in this study point to growth and loss alongside each other, I suggest explanatory frameworks need to incorporate both these facets of the cancer experience.

Legacy of lingering uncertainty

Doyle (2008) conducted an evolutionary concept analysis of the term 'cancer survivorship'. Uncertainty was one of five attributes identified. Dow (1990) argues that 'uncertainty is an inextricable part of surviving cancer' (1990: 514) whilst Vachon (2001) suggests that, for some survivors, uncertainty never goes away, 'that this fear does not decrease over time, but may become worse as one worries how long one's luck can last' (2001: 281). More recently, Miller (2012) explored the specific sources of uncertainty experienced during cancer survivorship, highlighting medical, personal and social sources of uncertainty unique to the cancer experience. Medical sources of uncertainty relate to diagnosis, treatment and prognosis, including variability and longevity of side effects. Personal sources of uncertainty relate to changes to one's sense of self, including conflicting identities, physical changes to self and career-related concerns. Social sources of uncertainty relate to communication and interaction with wider social networks, including family. This includes unpredictable interactions, disclosure and impact on future intimate and familial relationships. Miller concluded that uncertainty persists long after treatment completion and recommends that uncertainty should be managed throughout survivorship (Miller 2012). In contrast, research has also suggested that long-term survivors may have come to terms with, and moved on from, their cancer experience. The experience moves into the background and there is reduced concern about the impact of cancer on their lives – cancer is part of the past (Carter 1993, Miller *et al.* 2008).

Findings from this study corroborate those reported by Miller (2012), in particular the sense of *lingering uncertainty* that underpins the cancer experience, which

suggests uncertainty does persist into long-term survivorship. Evidence from this study demonstrates that lingering uncertainty manifests itself in different ways and to different extents during the long-term cancer survivorship phase. This includes fear and risk of recurrence, how long side effects will continue for, and will they worsen, will cancer be their cause of death, future sexual function and relationships, children's risk of developing cancer and being unable to plan for the future. For some it is a weak sense of uncertainty (e.g. Patricia and Claire) whereas other described a strong sense of uncertainty (e.g. Richard). As such, findings support Pelusi's conclusion that survivorship is an 'uncharted, ever-changing, nonpredictable journey' (1997: 1350).

The predominant manifestation of lingering uncertainty is fear of recurrence. Previous research has highlighted it as a concern for long-term cancer survivors (Deimling *et al.* 2006a, Cesario *et al.* 2010, Harrison *et al.* 2011, Department-of-Health 2012, Miller 2012). In a recent Department of Health pilot survey on the quality of life in cancer survivors in England, fear of recurrence and fear of dying were reported by cancer survivors at one year post-diagnosis (47% and 27% respectively). At five years post-diagnosis, fear of recurrence was reported by 42.5% of respondents whilst 22% reported an ongoing fear of dying (Department-of-Health 2012). As such, it could be said that the 'sword of Damocles' continues to hang over many people living long-term after a cancer diagnosis. People diagnosed with cancer have been made 'mortality salient'— they have confronted death and recognise that they will do so again at some point in the future, although they do not know when (Little and Sayers 2004b, Little and Sayers 2004a). This confrontation with death has 'disrupted their previous beliefs about life expectancy, making them insecure about how much time they may have left' (Rasmussen and Elverdam, 2007: 618). Indeed, Cesario *et al.* (2010) found that worry about recurrence and fear of death were expressed regardless of age or life stage in a sample of long-term ovarian cancer survivors. Women felt they were being denied a

future. Even those told they were cured expressed concern that cancer would return. As such, cancer was a constant threat (Cesario *et al.* 2010).

Conflicting findings have been reported regarding long-term survivors' perceived cause of cancer and fear of recurrence. It has been argued that developing a theory as to why cancer developed may provide a sense of security and reduce worry about recurrence (Dirksen 1995). However, a more recent study reported that perceived chance of recurrence was not associated with attribution of cause or prevention (Stewart *et al.* 2001). Findings from this study appear to corroborate Stewart *et al.*'s findings. Some participants who have attributed a cause to their cancer still have a strong fear of recurrence. This could be, in part, linked to hyper-vigilance. Horlick-Jones (2011) questions how survivors 'bracket' their fears about recurrence, and stop constantly checking for symptoms. Survivors have lost trust in their ability to look after their own health, which he refers to as a loss of 'everyday health competence' (Horlick-Jones 2011). Indeed, one of the themes in Breaden's (1997) study of living beyond cancer is 'the body as the house of suspicion' – women feel that their bodies have let them down. Some individuals in this study also described a loss of confidence about their own health. Horlick-Jones (2011) suggests survivors sometimes interpret mundane sensations as symptoms of recurrence. Kate is an exemplar case in this respect. She feels that HPV is the cause of her cancer. She has not engaged in a sexual relationship since her diagnosis, in part to protect herself from the spread of HPV. However, she still has a strong fear of recurrence and is hyper-vigilant, checking for blood in her urine every day.

Miller (2012) concluded that uncertainty experiences vary from person to person. This was certainly the case in this study, where all individuals experienced uncertainty to some extent, but some manifested a stronger sense of lingering uncertainty than others. Some sources of uncertainty were unique to the cancer experience, but some participants also described uncertainty relating to ageing,

particularly how their health status may be affected as they get older. Here we can see how an individual's life stage may influence their experience of uncertainty.

The place of cancer in long-term survivorship

Miller (2012: 439) argues that 'living with each source of uncertainty is challenging because it may persist, waxing and waning, throughout survivorship'. Similarly, in this study, so-called '*reality checks*' experienced by participants can result in the movement of cancer from the background to the foreground of their lives. These reminders of cancer have been discussed in other studies of long-term cancer survivorship, but only one study has explicitly explored 'triggers of uncertainty' (Gil *et al.* 2004). Similar to the participants in this study, Sekse *et al.* (2009) highlighted that 'although many [long-term gynaecological cancer survivors] said that they were more or less through with cancer, little was needed to spark distress or anxiety for a renewed threat' (2009: 293). In Gil *et al.*'s (2004) study, the most frequent triggers for long-term breast cancer survivors were hearing about somebody else diagnosed with cancer and new aches/pains. Other triggers included information about cancer in the media, follow-up appointments, annual mammograms, late effects of treatment, the anniversary of diagnosis and when a healthcare professional pays attention to a symptom - similar to the findings presented in this study. Over half of the participants mentioned pain/symptoms as a trigger, followed by side effects of treatment and meeting/talking to other people, or hearing of other people diagnosed with cancer. However, what this study adds is that broader life events, such as experiencing low or anxious points in life, can also act as a reminder of cancer. As such, the importance of wider personal and social context is stressed when considering when and why cancer fluctuates between the foreground and background of individuals' lives.

Typology of the place of cancer

My analysis identified three sub-groups that make up a typology describing the place of cancer in long-term cancer survivorship: cancer is in the '*past*', '*past-present*' or '*present-future*'.

Cancer in the 'past' group

Participants in the '*past*' group appear to have come to terms with, and moved on from, their cancer experience. The experience has moved into the background, for the most part, and there is reduced concern about the impact of cancer on their lives. This group shares features with what Mullan (1985) and subsequently Miller *et al.* (2008) refer to as '*permanent survival*'. This phase embodies 'a gradual sense or confidence that the risk of recurrence is low and that the chance of long-term survival is great' (Miller *et al.*, 2008: 372). Participants who fall into this group (Claire and Patricia) correspond with Miller *et al.*'s (2008) sub-category of '*cancer free-free of cancer*'. They are in remission and have experienced little '*fall-out*' (physical or emotional impact) as a result of cancer. In terms of the '*survivor*' identity, Claire has accepted that she is a '*survivor*' but has not internalised the '*survivor*' identity; it is not how she sees herself and would not describe herself as such. Patricia on the other hand has assimilated the '*survivor*' identity into who she is - being a cancer survivor is a positive part of her identity today.

Cancer in the 'past-present' group

The experiences described by participants who fall into the '*past-present*' group reflect those reported by Breaden (1997) who found that, on treatment completion, individuals feel they have not only survived cancer, but are also surviving the experience of cancer. Again, parallels can be seen with Miller *et al.*'s (2008) '*permanent survival*' phase, but participants in the '*past-present*' group fall into their second sub-category of '*cancer free-not free of cancer*'. They too are in

remission but continue to experience 'fall-out' from the disease (long-term and/or late effects of cancer and its treatment and fear of recurrence). Drawing on Tedeschi *et al.*'s (1998) resilience and thriving framework, participants in the 'past-present' group exhibit elements of their 'survival' sub-category – they have survived, but without regaining their previous level of functioning (Tedeschi *et al.* 1998). Once again, some of the participants in this group have accepted that they may be identified as 'survivors' but have not, and have no desire to, internalise the 'survivor' identity into their sense of self. Some, like Mary, do not want to be defined by their illness, whilst others, like Angela, do not feel their experience was severe enough to warrant such a label (Kaiser, 2008). Some participants in this group have, what Kaiser (2008) refers to as, 'crafted' new illness labels. For example, post-treatment, both Mary and Moira refer to themselves as 'well' rather than 'survivors'. However, others have adopted the 'survivor' label, and take pride in their identity as a cancer survivor.

Cancer in the 'present-future' group

It could be said that the participants in the 'present-future' group live in what Frank (1995) calls the 'remission society' – they are effectively well but could never be considered cured' (1995: 8). However, it is interesting to consider what is meant by 'well'. The individuals in this group are currently 'disease-free' – there is no evidence of active disease - therefore in this respect they are 'well'. This applies to Margaret and Andy – the disease episode is in the past and they do not experience side effects of treatment that affect physical functioning. However, neither Richard nor Roger believe they are 'cured'. In terms of the disease, they are 'well' - for now. However, they are not 'well' with respect to the side effects of cancer treatment they experience. Richard has urological problems and Roger experiences problems with sexual functioning. What they all have in common is a perception that they are 'living with' cancer *within* them, and it has the potential to affect them again in the future. The majority in this group, however, have not internalised the 'survivor'

identity and the label 'survivor' takes on a different meaning for this group. As Kaiser (2008) pointed out, for some people the label 'cancer survivor' does not sit well with them as life post-treatment can be challenging, particularly if the individual does not fit with the 'ideal type' i.e. fit, healthy, volunteering for charity, etc. (Kaiser, 2008). Whilst those in the '*past*' and '*past-present*' groups have survived cancer, Richard, for example, perceives himself as a survivor in the present tense – he is surviving cancer (both the disease and the experience of cancer). He is in a perpetual state of survival as he grapples with an ongoing fear of recurrence and the daily struggle to manage the consequences of treatment.

Throughout the findings chapters, I have discussed some of the contextual socio-demographic and cancer-related factors that may influence the place of cancer in participants' lives. It is difficult to make associations or draw conclusions about the impact of factors such as age, gender, cancer type and time since diagnosis on the place of cancer because findings are based on the accounts of a small sample of 13 participants. It is clear from the findings presented that for those living long-term after a cancer diagnosis the nature of the cancer experience is individualised. To understand the legacy of cancer requires a deep exploration of individuals' personal and social circumstances.

Building on existing models of survivorship

Fundamental to being able to put cancer (the disease) in the past is the five-year survival marker. The five-year marker was a key turning point for many participants and allowed them to draw a line under that particular cancer episode. Adopting a positive, optimistic attitude towards cancer also seem to enable participants to put the disease in the past. Cancer is in the present for those experiencing ongoing consequences of cancer and its treatment that affect physical functioning and body image, those living with a fear of recurrence or those actively engaged, on a regular basis, with cancer-related activities. The extent to which participants feel cancer will affect their future is, in part, driven by their perception of the cause, and course, of

the disease. Those that feel cancer is *within* them have a strong sense that cancer has the potential to affect their future. Either they do not feel they have been cured of the illness episode they experienced, or that particular episode has been successfully treated, but cancer still exists within them. These 'present-future' individuals therefore differ to those in the 'past-present' group, as the latter feel cancer (the disease) has gone – it is generally the physical consequences of cancer and its treatment that they live with today.

The typology/model of long-term survivorship that I have developed resonates in part with Miller *et al.*'s (2008) model of survivorship. However, an additional category is needed that reflects that, although the 'present-future' group have been told they are 'disease-free', they feel they are living with cancer *within* them. This additional category should reflect not only the ongoing state of surviving the experience of cancer, but also surviving the disease itself. Miller *et al.*'s (2008) model also does not account for the growth that can occur as a result of the 'fall-out' of the disease, as evidenced by the simultaneous benefits and losses experienced by the majority of participants in this study, across the three sub-groups of the typology.

It is important to position the analysis within the broader methodological and philosophical underpinnings of the study. The stories generated between the participants and myself were active; co-constructed. Therefore, I reiterate the situated nature of the accounts interpreted and presented in this thesis. My interpretation of the place of cancer in participants' lives is reflected in the stories they shared at a particular point in time in their cancer trajectory and wider life course. Had they been interviewed at another time, by another researcher, their stories, and the interpretation of their cancer experience, are likely to have been different, hence the situated nature of accounts. Building a typology is a descriptive tool to aid cross-case analysis; to explore the experience of long-term cancer survivorship at the aggregate level. Therefore, reflecting on the situated nature of

the cancer experience, the place of cancer highlighted here, be it in the past, present or future is not fixed or static; it has changed over time, and is likely to do so again. For example, Angela was borderline between the 'past', and 'past-present' groups. She described her cancer as '*relatively minor*', that it has now gone and that she has actually grown as a result of the experience. However, she now experiences bone-thinning, which is possibly a consequence of radiotherapy and hormone therapy. This has led to a nervousness about her ability to remain active in the future, and may restrict her activities. As a result of this deterioration in bone density Angela is in the 'past-present' group. Had I interviewed Angela a couple of years previously, she may well have fallen into the 'past' group, as bone-thinning is something she has experienced during the long-term survivorship phase. Her case serves to demonstrate the potential late effects of cancer treatment and how the place of cancer can shift over time.

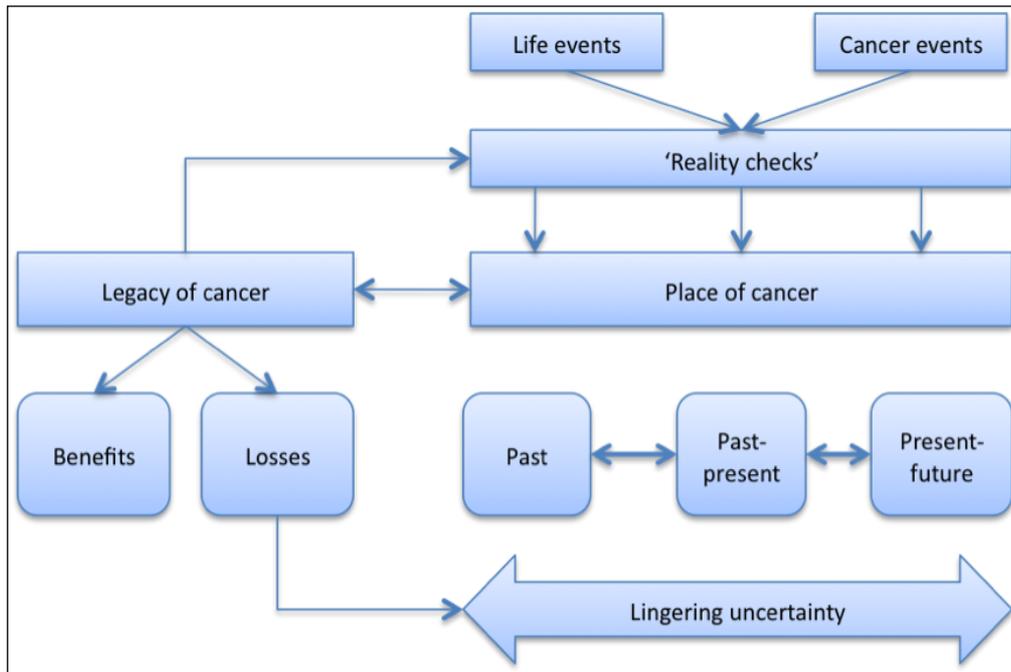
In addition, drawing on the findings presented in this chapter, the sense of lingering uncertainty, alongside 'reality checks' described by participants, reiterates further that the place of cancer is not fixed. Not only can it oscillate between the past, present and future, but also between the foreground and background of participants' lives. Cancer events, '*reality checks*' or other life events can mean cancer moves from the background of participants' minds to the foreground, interrupting the project of putting cancer in the past and, thus, their ability to move forward from the cancer experience. For the majority of participants in this study, cancer and its consequences were not something that affected them on a daily basis. However, all participants described reminders of cancer that bring it to the foreground of their minds, be it checking for symptoms of recurrence such as blood in stools or urine, or experiencing the side effects of treatment, such as infections, impotence, fatigue or irregular bowel functioning. These 'reality checks' prevent participants from keeping cancer and its consequences in the background and impacting their ability to engage in activities and pursuits of daily living. This highlights the tension experienced by those living long-term after a cancer

diagnosis. For the most part, the majority can get on with living but from time to time they are reminded of the fact that they were diagnosed with cancer, and this brings the disease, and the experience of it, to the forefront of their minds. What this study has shown is that this uncertainty and unpredictability lasts long after treatment completion. Here we can link back to the legacy of benefits and losses experienced by individuals diagnosed with cancer highlighted in this study. Whilst there are positives to be taken from the cancer experience, these exist alongside losses that, intermittently, serve to remind individuals that they were diagnosed with not just a life-threatening, but sometimes life-altering, disease. In a recent report, Macmillan Cancer Support referred to this legacy as 'the true cost of being cured' (Macmillan-Cancer-Support 2013).

Summary of the experience of long-term cancer survivorship

Figure 9.7 demonstrates how the different elements of the cancer experience interact and influence the place of cancer in long-term cancer survivorship. Cancer has left a legacy of benefits and losses which continues to impact individuals' sense of self, outlook on life, relationships and daily functioning. The place of cancer, be it in the 'past', 'past-present' or 'present-future', is underpinned by varied manifestations of *lingering uncertainty* and influenced by '*reality checks*' experienced during this phase of the survivorship trajectory.

Figure 9.7: The experience of long-term survivorship



However, the place of cancer in the lives of those living long-term after a cancer diagnosis is not static, oscillating between the past, present and future and foreground and background of participants' lives. There is evidence of oscillation in the wider chronic illness and medical sociological literature. For example, Little *et al.* (1998) refer to 'fluctuation' between disturbances and resolution, whilst Frank (1995) alludes to an 'oscillating trajectory', whereby individuals move between states of 'wellness' and 'illness'. Individuals experience periods of illness in the 'foreground' and 'background' of an overall state of 'wellness' (Frank 1995). Frank uses the metaphor of 'illness as travel' – where individuals with chronic illness have 'dual citizenship' of well and sick (Frank, 1995: 9). There is also evidence in the chronic illness and cancer literature of oscillating manifestations of uncertainty that challenge those living after a cancer diagnosis (Mishel 1990, Mishel *et al.* 2005, Miller 2012).

As such, the findings support Pelusi's (1997) assertion that survivorship is a 'dynamic, life-long process' (1997: 1353). Cancer is ongoing for the majority of

participants in this study, a finding also reported in previous studies (Pelusi 1997, Costain Schou and Hewison 1999, Zebrack 2000a, Bowman *et al.* 2003, Sinding and Gray 2004). For some, cancer is 'immediate and present' (Thomas-Maclean 2005). For others, cancer comes to the foreground when they experience '*reality checks*' that remind them of their cancer experience. These triggers highlight the dynamism and fragility of the place of cancer in participants' lives.

The following chapter explores the utility of liminality as a framework for understanding the experience of long-term survivorship. As liminality is characterised by ambiguity, uncertainty and contradiction, the duality of benefits and losses, oscillating place of cancer and manifestations of lingering uncertainty in the lives of those living five years or more after a cancer diagnosis provide a useful starting point for exploring the theory.

Chapter 10. Theoretical discussion: Liminality and long-term cancer survivorship

Introduction: liminality - recap of the theory

Drawing on findings from this study, in this chapter I explore the utility and applicability of liminality as a framework for understanding the illness experience during the long-term cancer survivorship phase (five years or more post-treatment).

To recap, liminality is a state of being, where individuals find themselves 'in-between' social positions - on the threshold, or margins, of society. This can be an ambiguous time, characterised by uncertainty and contradiction, as individuals strive to transition out of the liminal state and into a new social position. Little *et al.* (1998) developed the concept of liminality within the context of cancer, delineating 'elements' of the liminal experience: 'cancer patientness', 'communicative alienation' and 'boundedness'. These elements have been supported, to some extent, in research by Thompson (2007). Little *et al.* (1998) also argue that the liminal state is a permanent one - that individuals live in a state of 'sustained' liminality that persists until the end-of-life. This is in contrast to van Gennep's (1960) original 'rites of passage' model where those in the liminal phase ultimately transition out (reincorporate) into a higher social status. Whilst Navon and Morag (2004) and Thompson (2007) support Little *et al.*'s assertion, Crouch and McKenzie (2006) suggest a third phase that 'transcends' 'sustained' liminality and is experienced by long-term cancer survivors (those five years or more post-diagnosis). Crouch and McKenzie's conceptualisation is akin to van Gennep's original model, however, it appears to be somewhat aspirational for most long-term survivors as they 'yearn' to get back to normal, but may not reach that state.

Methodological limitations and gaps in the current evidence base, highlighted in the literature review (Chapter 4), meant it was unclear whether liminality is a pertinent

framework for understanding experiences of long-term cancer survivorship. This being said, findings from studies including long-term survivors (Little *et al.* 1998, Crouch and McKenzie 2000, McKenzie 2004) suggested liminality does show utility and should be explored further. Therefore, drawing on findings from this study, a discussion of the applicability of liminality as a framework for understanding long-term survivorship is presented here. In the following discussion, I explore whether Little *et al.*'s (1998) elements of liminality are present in the narratives of individuals living long-term after a cancer diagnosis, and whether the premise of 'sustained' liminality holds true during this phase of the survivorship trajectory. To conclude, suggestions for theory development are presented.

Do participants experience Little *et al.*'s elements of liminality?

There is evidence in the narrative accounts of those diagnosed with cancer of Little *et al.*'s (1998) elements of liminality. As the discussion will highlight, there are positive, as well as negative, implications to experiencing these liminal elements.

'Cancer patientness'

Based on findings from this study, I argue that the discussion needs to move beyond the idea of 'cancer patientness' to explore further the concept of 'cancer survivorship' and being a 'cancer survivor'. Whilst a minority in this study identify with being a 'cancer patient', most were more likely to acknowledge that they are a 'cancer survivor'. This being said, Moira said that although she would describe herself as '*well*' she will always be a cancer patient. Claire mentioned that she feels like a cancer patient at follow-up appointments.

Whilst most participants in this study accept that they are labelled a 'survivor' by wider society, they do not necessarily identify with the term themselves. Only a

minority has integrated the survivor identity into who they are today and would refer to themselves as such. Those who did not identify with the term were quite clear on that and not afraid to voice their opinion about it. For example, Mary said she hated the term, whilst Malcolm said that he had not changed in any way as a result of his diagnosis. He was treated for a disease, nothing more. Claire, like Margaret and Angela, acknowledges that whilst she is a survivor she would not want to be labelled by her illness and would not necessarily refer to herself in those terms. Some participants compare themselves to others (with cancer or other illnesses) and perceive others as worse off, or more deserving of the label, or feel that they have done no more than anyone else would have in the same situation. Some individuals, like Roger, do not endorse the term 'survivor' as it implies they are cured, which they do not feel is the case. Several participants also do not endorse the 'battle' analogy as it implies that those who die from cancer did not fight hard enough.

At the other end of the scale, there are those like Patricia, Janet and Kate who strongly endorse the term 'cancer survivor' - being a 'cancer survivor' is part of who they are. They are proud of the way they handled themselves, and have gained new-found strength and confidence from their survivorship. They are happy to identify themselves, and be identified by others, as a 'cancer survivor'. Finally, there are those who are 'surviving' cancer, like Richard. He described himself a survivor, but it reflects an ongoing sense that he is not 'free' of cancer and therefore continues to survive it.

The shift away from identifying as a 'patient' stems from the fact that participants generally associate the term with diagnosis and treatment. This resonates with research by Kelly *et al.* (2011) who explored the meaning of cancer survivorship to people with and without a history of cancer. They suggested that, for those with a history of cancer, treatment completion was a "rite of passage" which initiated 'a shift from the patient identity, which may have negative connotations, to the more

positive identity of survivor' (2011: 165). However, only a minority of the individuals in this study has integrated the 'survivor identity' into their self-concept. The majority would refer to themselves as cancer survivors when talking about their illness experience, but would not say it defines who they are today. Low illness centrality (how much current identity is centred around the cancer experience) has also been reported in a recent study on long-term survivors of breast cancer (Helgeson 2011).

Findings presented here resonate with those reported in the only other UK-based study recently conducted which explored acceptance of the 'cancer survivor' identity in a sample of long-term breast, colorectal and prostate cancer survivors (Khan *et al.* 2012). Like the participants in this study, many accepted that they were a survivor because they had been treated and survived the disease. They also suggested people reject the term because it implies cure. UK-based studies such as this one and Khan *et al.*'s (2012) contradict those from the US where the advocacy-based movement coined the term 'cancer survivor' to empower people affected by the disease to take ownership of their treatment and care. My findings point to, at the least, ambivalence about the term and, at the most, hatred. Khan *et al.* (2012) go as far as to say that the term 'survivor' should be avoided and that more 'descriptive' terminology be used when discussing this population, such as people who are five years or more post-diagnosis (Khan *et al.* 2012).

'Communicative alienation'

Not all participants described experiences of 'communicative alienation', but the majority did. For some, these were one-off events, but for others it appears to be ongoing. For example, Claire described how her partner had not met her 'expectations' when she reached the five-year marker:

Claire (follow-up interview): ... if I'm completely honest, I felt very let down actually by my partner and we had a bit of problem with that this year, cos it was only this year. Yeah, he knew how important it was to me and I felt that he didn't support it, in the way I feel he should have. Again, you know, you can look at in different ways, that maybe he felt that he had, but my expectations were a little bit higher, I don't know. It's one of those... but I did feel that he let me down when he has always known that this was a big marker point for me.

Sue experiences varied manifestations of 'communicative alienation' within a social and professional context. She puts on a '*façade*' for her mother and daughter, as her mother worries when Sue becomes ill and her daughter '*would walk out of the room at the mention of the word cancer*'. As a result, Sue censors what she shares with her family. Also, as described by her husband, Sue carries a '*heavy load*' as a result of her role at a cancer charity. She talks to her husband but he feels there is only so much he can do to support her. Sue also mentioned that she does not share her own personal experiences of cancer with people she encounters through her support role, as she understands that they want to hear about people who have been in a similar position. It seems Angela has to present herself in a socially acceptable way – she needs to be seen to be coping, particularly as her friends see her as an '*inspiration*'. She said that friends would not want to see her '*wallowing*'. Malcolm described a sense of '*cancer fatigue*' amongst his friends, in that they do not want to hear or talk about cancer anymore.

Mary said that whilst she and her husband talk, they hold back, as a way of protecting one another. She mentioned that she is very open about death and dying, often making remarks '*in jest*', but it makes her family uncomfortable so she tries to talk about it in a different way. Her family have been made 'death salient' and it makes them feel uncomfortable (Little and Sayers 2004a). Kate is secretive about her cancer diagnosis. She has not told her child that she had cancer, and only shares her experiences with those who have been through similar struggles. This is, in part, because she wants to talk to people who will understand what she has been through, but also because she is worried about peoples' reaction to the fact that

she had what she feels people perceive as a *'dirty cancer'*. Richard mentioned that his children avoid asking him questions for fear they will say the wrong thing or upset him. He, like Andy, specifically mentioned that if you have not been through cancer, you cannot fully understand what it is like to go through, and live with, that experience. Indeed, Janet's narrative did not seem to exhibit any evidence of 'communicative alienation', perhaps because, as she said, her husband was also a 'cancer survivor' so could understand what she was going through because he had been through it too.

Despite the negative impact, there are also positive implications to experiencing 'communicative alienation'. 'Communicative alienation' has led some participants to seek out other people who have been affected by cancer – people who will be able to understand what they have been through. 'Communitas' is the type of 'community' that is found during the liminal period (Froggatt 1997). Individuals during the liminal stage relate to each other as equals, regardless of role or status, because they are 'cognizant of their common liminal or marginal situation and experiences' (Bloom, 1997: 468). They understand each other and their experiences and, as such, are a source of social support, which 'tempers the isolation of liminality and marginalisation' (Bloom, 1997: 468).

All participants in this study described 'communitas' in some way. Seven of the thirteen are engaged with cancer charities through volunteering, campaigning, peer support, etc. and want to meet other people who have survived cancer. Three of the remaining six said they now have a greater understanding or empathy with other people who have been diagnosed but are not actively involved with meeting or supporting others. The other three access or offer peer support, but on their own terms i.e. not with charities but through friends. Claire turns to her 'Hospital friends' for peer support. Mary got involved with a hospital patient experience group and runs a support group. Like Mary, Patricia is involved with cancer charities because she wants to see service improvements for women with breast cancer, but

meeting other women also gives her the confidence and reassurance to say she has survived. Whilst Moira did not describe 'communicative alienation' from her family and close friends, she feels the need to seek out other women with breast cancer. Through her involvement with cancer charities she has developed new relationships and formed a '*connection*' with these women, which is a source of comfort to her.

'Boundedness'

'Boundedness' appears to be the most pronounced of Little *et al.*'s (1998) elements, with all thirteen participants describing this element in their narratives. However, as with the other elements, the degree of 'boundedness', and its implications, varies from participant to participant. Cancer has led to a loss of certainty for Sue about her future health. She feels she is vulnerable to developing other cancers and therefore has an ongoing fear of recurrence. Most interestingly, she said she has to '*live within my boundaries*' now as a result of '*chemo-fever*' (fatigue). This affects her ability to work, as she can now only work part-time, and her social functioning. Mary said that she is living on '*borrowed time*'. She feels she is more likely to have cancer again than not, and thus experiences an ongoing fear of recurrence and loss of certainty about her future health. Her life has also become more pressured as a result of her involvement with a cancer support group and hospital patient experience group. In effect, she is bound within the cancer '*world*' – a world that she would like to extricate herself from so she can focus on her life beyond cancer.

Kate described a legacy of cancer that centres on fear. She too has an ongoing fear of recurrence and, as such, is '*hyper-vigilant*', checking for blood in her urine every day. She described a powerlessness and passivity around cancer, which has subsided over time but is still evident in her life today, particularly in terms of ongoing relationship and intimacy concerns. Socially, she is very much bound by her cancer experience, as she feels other perceive her cancer as a '*dirty cancer*'. Janet feels she is '*prone*' to cancer. She has a '*niggling fear*' that cancer will come back

and therefore her narrative suggests that she is bound by the ongoing fear of recurrence. She also described a loss of power. As she does not know what caused her cancer, she is powerless to do anything specific to prevent recurrence.

Moira said that cancer is attached to her, which is a clear example of 'boundedness'. Her narrative demonstrated a loss of confidence regarding her body image. She is restricted in the summer, both socially and spatially, as she continues to wear a prosthesis that signals to those around her that she has had cancer. Angela said recent bone-thinning means she is worried about whether the effects of cancer treatment will restrict her active lifestyle in the future. Whilst Malcolm accepts the consequences of cancer treatment as an '*annoyance*', he is bound, spatially, in terms of travel. He cannot travel long-haul as a result of ongoing bowel functioning problems. Richard described how he will never be '*free*' of cancer. Therefore, it seems he will always be bound by the disease. Spatially, he is limited as he experiences ongoing mobility issues which means he is at home more, and must be near a clean toilet at all times. Like Malcolm, he cannot travel long distances and has had to give up social activities like golf and gardening. Interestingly, he described cancer as '*insidious*' as it affects the family – this suggests a sense of 'boundedness' exists not just for the person diagnosed, but the wider family as well.

Roger feels he has '*remnants*' of cancer within him, and thus he is living with cancer. He is therefore bound by the disease, as it is within him. He also experiences a sense of 'boundedness' in terms of impaired sexual functioning, although this has become less of a concern as he has gotten older. Margaret suggested that cancer could be '*dormant*' and as such she should acknowledge that she is living with cancer. She too is bound by the disease. She is concerned about developing other cancers, such as colorectal cancer, rather than a recurrence of breast cancer. Finally, Andy feels that cancer could be '*brewing*' or '*floating*' around his body, so he described a real sense of being bound by the disease as it is within him. He does

not feel that cancer ever goes away and as such lives with a strong, ongoing fear of recurrence, and associated fear of death and dying, which is exacerbated when he is ill.

Positive implications of 'boundedness' were also evident in the narratives. Sue experiences a sense of 'boundedness' through working for a cancer charity, which results in a constant reminder of cancer in her daily life. However, her job provides her with a '*rational knowledge*' of ovarian cancer, which has helped reduce (but not eliminate) her fear of recurrence. Angela continues to attend follow-up appointments, which Little *et al.* (1998) suggest creates a sense of spatial 'boundedness'. However, Angela finds being under this '*umbrella*' reassuring as it has a protective function. Participants like Angela, Moira, Roger and Andy want to maintain that sense of 'boundedness' because they feel they are being monitored for signs and symptoms of recurrence. Richard talked about how he has '*encapsulated*' his life which is a clear manifestation of 'boundedness'. However, rather than being construed negatively, it has been a positive development for Richard as it means he now focuses on the important things in his life, namely his family. He said he has no need for some of the material possessions he has collected. His life is much simpler now and he is happier and more content as a result.

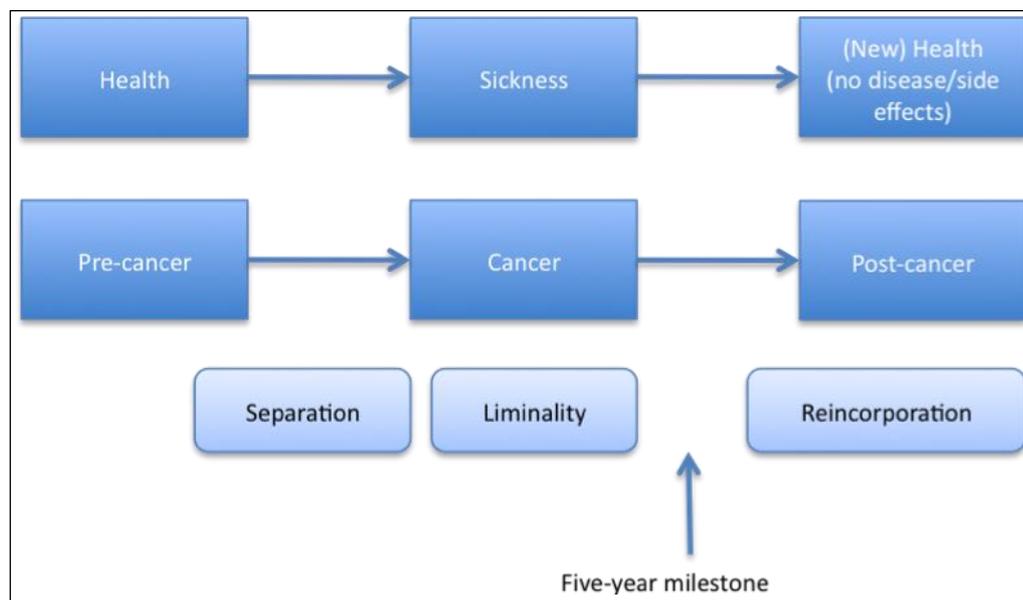
Do participants live in a state of 'sustained' liminality?

Most of the participants in this study described, to varying extents, elements of Little *et al.*'s (1998) liminality. A sense of 'communitas' has also been identified. However, I argue in the following section that most, but not all, individuals living long-term after a cancer diagnosis live in a state of 'sustained' liminality.

Returning to van Gennep's (1960) original rites of passage model, and drawing on my typology of the place of cancer, I suggest that those for whom cancer is in the

'past' (Claire and Patricia) have transitioned out of the state of 'sustained' liminality, and reincorporated into a new state of 'health' or 'wellness' – as per Crouch and McKenzie's (2006) assertion. I argue, using Claire as an exemplar case, that those in the 'past' group have successfully gone through a rite of passage, and the turning point that facilitated transition out of the liminal stage was reaching the five-year marker (Figure 10.1).

Figure 10.1: Rite of passage for individuals for whom cancer is in the 'past'



Exemplar case: Claire

The five-year marker was a turning point for Claire. Cancer had '*consumed*' her up to that point. For example, she experienced post-traumatic distress in the transition period. However, she focused on the five-year point, drawing on the statistics associated with the milestone. Claire discussed how she feels her chances of developing cancer again are the same as everyone else. By reaching the five-year point and not experiencing side effects of treatment, along with her optimistic attitude and positive outlook on life, Claire has been able to put cancer behind her.

Claire (first interview): 'I put this thing on my five year marker. I just sort of draw a line under it now really and just try and forget about it... It's sort of not really part of your life any more now, which is really quite nice. It is a bit of a relief and, like I said, the fact that you go back statistically to how everyone else is then you just sort of go "well, if I'm going to be dealt the card again, I'm going to be dealt the card again", but that's that.'

Those for whom cancer is in the 'past-present' and 'present-future' continue to live in a state of 'sustained' liminality. However, what that means for those who are in these groups, differs. Those in the 'past-present' group have been able to put the specific cancer episode (disease) in the past (survived cancer), but the ongoing consequences of cancer and its treatment mean that cancer remains in the present (surviving the experience of cancer). These individuals live in a state of 'sustained' liminality because they are on the threshold, or in-between, sickness and wellness. Findings from this study suggest 'sustained' liminality can be conceptualised in two ways. As a result of the consequences of treatment, participants can experience liminality *physically*, for example, fatigue, bladder and bowel dysfunction and body image concerns. As a result of the disease itself, participants may also experience liminality *existentially*, in terms of fear of recurrence and a sense of being 'potentially ill' (Drew 2003). Based on the narratives shared, I would argue that Sue, Kate, Janet and Moira experience both physical and existential liminality (see exemplar case below), whilst Mary experiences existential liminality and Malcolm and Angela experience physical liminality.

Exemplar case: Kate

Kate's narrative is one of extreme gains and losses. Despite gains in terms of self, outlook and relationships with friends, Kate's life is clouded by the 'legacy' of cervical cancer, particularly relating to sexual function and relationships, and bowel and bladder function. However, reaching the five-year marker gave Kate the confidence to say she had survived that illness episode. She said that cancer had controlled her life up to that point but 'officially' she is likely to be ok now. This being said, she still has a strong fear of recurrence, which manifests itself through daily checking for symptoms.

Kate (follow-up interview): Apart from the bladder legacy, which terrifies me and makes me think about cancer, about blood, I would say I do think about it every day because I'm constantly looking at my urine and thinking "is it pink?"

Like some of those in the 'past-present' group, individuals in the 'present-future' group are 'potentially ill' (Drew 2003) and therefore live in a state of 'sustained' liminality. However, 'sustained' liminality means something different to this group as they feel they are living with cancer *within* them. As such, they predominantly experience existential liminality. However, Roger and Richard also described elements of physical liminality (sexual dysfunction and urological problems respectively). This generates a strong sense of lingering uncertainty in most of the individuals in this group. Margaret is the exception. She did not exhibit a strong sense of lingering uncertainty, but has more recently begun to acknowledge that cancer could come back, having lain 'dormant' within her for many years. Richard's case demonstrates well the ongoing existential and physical impact of cancer on his life.

Exemplar case: Richard

Richard's narrative was one of gains and losses. His narrative highlighted positive changes to his sense of self and relationships, as well as his life philosophy. Richard has '*encapsulated*' his life – focusing on the people and activities he enjoys, which has brought happiness and contentment. These benefits are mediated by the fact that Richard feels cancer is '*insidious*' – it not only affects him, but his family as well. A loss of physical functioning and poorer health overall restricts Richard's life today. In addition, fear of recurrence means Richard lives with an uncertainty about the future. He is aware that he could be affected by cancer again and fears cancer '*will pop up somewhere, some time.*'

Richard (follow-up interview): ...I know you probably hear about this quite a lot, 5 years is some kind of hurdle. Well it is a hurdle, but it's not the end. It's a theoretical hurdle. I know people who've been clear for 5 years and then 2 years later died. So, you know, you're never free, you can't say "I am free of cancer" you can say "at the moment I'm free of cancer."

What differentiates those who live in a state of 'sustained' liminality from those who do not?

Most of the participants in this study live in a state of 'sustained' liminality, predominantly due to an ongoing sense that they are 'potentially ill' (Drew 2003) (surviving cancer) but also as a result of the consequences of cancer treatment (surviving the experience of cancer). As such, individuals may experience physical and/or existential liminality, living 'in-between' sickness and wellness. However, two of the thirteen participants in this study do not live in a state of 'sustained' liminality – they have transitioned out of the liminal stage and reincorporated into a state of health or 'wellness'. This is akin to the original rites of passage model, and described by Crouch and McKenzie (2006) as a third stage after 'sustained'

liminality. I suggest that Claire and Patricia have been able to transition out of the liminal stage because they have been able to put cancer in the past. They do not experience side effects of treatment, have a low fear of recurrence and experience little lingering uncertainty. They adopt an optimistic coping style. They also saw cancer as a challenge, a hurdle to overcome which, having done so, has made them stronger. They do not experience Little *et al.*'s (1998) elements of liminality to the same extent as those in the 'past-present' and 'present-future' groups but, where they have, it has generally resulted in positive change. For example, Patricia very much sees herself as a cancer survivor and it is part of who she is today – she is proud of the way she handled herself and is a stronger person as a result of her diagnosis. Whilst Claire experienced some 'communicative alienation' from her partner at the five-year marker, she drew on peer support (her 'communitas') as they understood the meaning of the milestone.

The importance of closure

It is my interpretation that the five/ten-year marker, often emphasised by healthcare professionals and survival statistics, facilitated some closure with respect to the disease itself because it created the 'clear and stable' situation that participants had been aiming for. Reaching this time point meant that they could feel more confident that the specific illness episode was now over. However, some participants in the 'past-present' group have not gained closure with respect to their fear of recurrence. In this sense their situation is not 'clear and stable'. Complete closure was not possible for those who have been unable to formulate an explanation as to why they developed cancer, and therefore cannot do anything specific to prevent recurrence. They have not found a satisfying explanation for their illness (Wilson *et al.* 2007) and, as a result, experience existential liminality. Complete closure is also not possible for those who experience the ongoing consequences of treatment, as they do not know how long side effects will continue, when they will strike or whether they will get worse. Therefore, the sense

of lingering uncertainty that existential and physical liminality instils means that complete closure is not possible – and therefore ‘sustained’ liminality persists. Essentially, whilst individuals in the ‘past-present’ group feel they have survived the disease episode, they are still surviving the experience of cancer.

There was no real closure, or possibility for successful closure, for the ‘present-future’ group, who also live in a state of ‘sustained’ liminality. The four participants in this group described different manifestations of lingering uncertainty, but the predominant manifestation was the sense that they are living with cancer *within* them. As a result, they experience liminality existentially. The situation for these four individuals is not clear and stable (Wilson *et al.* 2007). The five/ten year marker did not provide the reassurance and resultant closure experienced by most of those in the ‘past’ and ‘past-present’ groups. Margaret was diagnosed some time ago but recalled that the aim was to reach five years of survival. However, she happened to miss an appointment and just stopped attending follow-up so did not receive closure with regard to her original diagnosis. Today, she feels that she is ok, but wonders for how much longer. Roger was discharged from follow-up after ten years and, although he was elated, he wondered ‘*what if they are wrong?*’ Andy found the five-year point ‘*unsettling*’ and Richard said that the five-year point was a theoretical marker and that he was free of cancer ‘*at the moment*’. Therefore, for the ‘present-future’ group, not only do they continue to survive the experience of cancer, for example, through ongoing consequences of treatment, but they also continue to survive the disease itself.

Wilson *et al.* (2007) concluded that an exit interview at the end of the clinical trial facilitated closure, and transition beyond treatment. At the end of treatment for cancer there is a need to mark the end of the ‘cancer patient’ role. At the end of follow-up, there is also a need for successful separation from the NHS/follow-up and transition into life post-cancer, as a ‘cancer survivor’/someone who is ‘well’. Indeed, Harrison *et al.* (2011) found that dissatisfaction with discharge was a

predictor of unmet need in long-term cancer survivors. The end of follow-up at five or ten years post-treatment can result in a sense of separation (akin to a rite of passage within the overall health-sickness-health rite of passage). For some, this separation can be positive, as it facilitates moving forward after cancer. However, for others, there is a question mark regarding 'where do I go for advice if I need it?' Some will 'reincorporate' into the healthcare system, for example, if they have a knowledgeable GP, if they are referred to other healthcare professionals, or if they become involved with cancer charities, etc. However, others, as demonstrated in this study, will continue to exist on the threshold between sickness and health and not know where to turn for further support to manage their physical and existential concerns.

Liminality: Suggested theoretical developments

Findings from this study suggest that not all participants live in a permanent state of 'sustained' liminality, as has been previously suggested (Little *et al.* 1998, Navon and Morag 2004, Thompson 2007). Those in the 'past' group experience little lingering uncertainty and few instances of Little *et al.*'s liminal elements. They have been able to transition out of the liminal stage into a new state of health/wellness as per the original rites of passage model (Van Gennep 1960) as they no longer occupy the 'sick role'. They have reincorporated into society at a higher level of consciousness, as the experience has made them stronger and more confident. Perceiving the five-year survival marker as a '*milestone*' or turning point, experiencing few side effects of treatment and a low fear of recurrence are key to enabling transition out of the liminal state. Essentially, those in the 'past' group have achieved closure. As per Wilson *et al.* (2007) their situation is now clear and stable, they experienced good endings and marked those endings formally. I suggest that there are parallels between the rites of passage model and post-traumatic growth theory, whereby some individuals are able to convert trauma into growth (Tedeschi and Calhoun 1995). Post-traumatic growth is defined by Tedeschi

and Calhoun (1995) as transformation to self, relationships and philosophy of life, leading to a higher level of consciousness.

There is evidence of all three elements of Little *et al.*'s (1998) liminality in the narratives of the participants in the 'past-present' and 'present-future' groups. The degree to which participants experience the elements of 'cancer patientness', 'communicative alienation' and 'boundedness' varies, as do their implications. Little *et al.*'s (1998) elements can be construed quite negatively and, whilst this has been shown to be the case in this study, findings here also support Thompson's (2007) assertion that liminality can be a catalyst for positive change – to self, outlook on life and relationships. Turner's (1967, 1969) original conceptualisation of liminality also suggests that the liminal phase has generative potential. In this study, 'communicative alienation' has lead participants to search for a connection with others who have been through the cancer experience. This 'communitas' can result in new friendships and opportunities, including volunteering, campaigning, etc. Likewise, a minority of participants have internalised the 'cancer survivor' identity into their personal and social selves, taking pride in their survival and acknowledging that being a cancer survivor is an important part of who they are. Even a sense of 'boundedness', in terms of leading a more restrictive lifestyle, can have its benefits. For example, Richard has '*encapsulated*' his life, focusing on his family and the activities that are important to him. As a result, he said he is much happier and more content. Therefore, this study argues that transformation is not just limited to those who have been able to transition out of the liminal stage. Those that still live in a state of 'sustained' liminality can also experience growth and transformation. This idea of gains and losses experienced by those living in a state of liminality links well with the suggestion that simultaneous benefits and losses are experienced after a cancer diagnosis, as already discussed in Chapter 9.

What this study adds to the theoretical discussion is the idea that, post-treatment, there is a move away from 'cancer patientness' to 'cancer survivorship'. However,

the 'survivor' identity is only adopted by a minority of participants. Whilst it is generally accepted that individuals diagnosed with cancer are referred to as 'survivors' it does not resonate with most of the participants in this study and, as a result, they do not want to be labelled as such. 'Communicative alienation' is not as evident perhaps as much as it might have been closer to diagnosis and treatment (beyond the scope of this study to explore), but there is still evidence of putting on a façade for family and friends, experiencing a lack of understanding from those who have not been through the cancer experience and concerns about how others perceive those affected by cancer. 'Boundedness' is perhaps the strongest element in participants' narratives. Examples of spatial 'boundedness', as a result of physical limitations, were described. For example, being unable to travel long-haul, having to avoid eating certain foods, living within one's '*boundaries*' and being unable to engage in certain physical and social activities. Examples of 'boundedness' also relate to the contraction of time: feeling on '*borrowed time*' or being robbed of future life expectancy.

'Sustained' liminality is therefore experienced by those in the 'past-present' and 'present-future' groups. Based on findings from this study, 'sustained' liminality has two facets: it can be experienced physically (surviving the experience of cancer) and/or existentially (surviving cancer – the disease). Individuals may have been able to put cancer (the disease) in the past, but if they experience the ongoing consequences of treatment that affect them physically they may wonder whether these side effects will continue indefinitely, or worsen. This sense of lingering uncertainty perpetuates living in a state of 'sustained' liminality. Existentially, some participants experience an ongoing fear of recurrence. Their sense of lingering uncertainty stems from them being 'potentially ill' (Drew 2003), either from the same cancer or feeling vulnerable to other cancers.

I argue that closure is key to transition, be it from the liminal state into a social state of health/wellness or a higher state of consciousness as per those in the 'past'

group, or being able to put the specific cancer episode in the past as in the case of the 'past-present' group. It is therefore important to consider how to facilitate closure (See Chapter 11: Conclusions - Implications for Practice). I conclude that liminality does have utility in understanding the experience of long-term cancer survivorship.

Quality in qualitative research - reflexive awareness

Adopting a subtle realist approach, a judgement has to be made regarding the credibility of research, particularly if it is to be used to inform policy and practice (Hammersley 1992). Likewise, the interpretivist approach, which focuses on seeking to understand and interpret human behaviour, requires me to think reflexively about my position in the research and the impact this has had on the stories constructed and interpretations made. As already briefly discussed in Chapter 5, Figure 10.2 outlines Green and Thorogood's (2004) suggestions for achieving 'reflexive awareness', the aim of which is to persuade the reader of the trustworthiness of findings. Taking these strands of 'reflexive awareness', and drawing on my reflexive and methods logs, I have produced a 'narrative account' of my research practice (Anspach, 1993: 182). This approach has been used in other studies adopting a multiple-case study design. In a study exploring rites of passage for individuals on kidney dialysis 'the criteria of reflexivity, voice and verisimilitude established the rigor of the study' (Martin-McDonald and Biernoff, 2002: 347).

Figure 10.2: Reflexive awareness

Methodological openness – being explicit about the steps taken in the data production and analysis, the decisions made, and the alternatives not pursued

Theoretical openness – the theoretical starting points and assumptions made should be addressed, and the ways in which they shaped the study accounted for

Awareness of the social setting of the research itself – in interviews or participatory fieldwork, the “data” are largely the results of interactions between the researcher and the researched. Reflexivity requires a constant awareness of this, and the ways in which the data result from these particular interactions.

Awareness of the wider social context - this might include awareness of how political or social values have both made possible the research and constrained it, and how the historical and policy contexts shape the data.

Methodological openness

Riessman (2008) suggests that, to persuade the reader, researchers need to ‘demonstrate the data are genuine, and analytic interpretations of them are plausible, reasonable, and convincing’ (2008: 191). The persuasiveness of findings is strengthened when ‘the investigator’s theoretical claims are supported with evidence from informants’ accounts, negative cases are included, and alternative interpretations considered’ (Riessman, 2008: 191). However, Riessman suggests caution should be exercised when citing quotations. Segments from interviews should include ‘contexts of production’ (2008: 191), so the response can be judged with respect to the question posed by the researcher. Ways to achieve methodological openness, and evidence to demonstrate I have achieved it, are outlined in Table 10.1.

Table 10.1: Evidence of methodological openness in this study

Achieving methodological openness		Evidence of methodological openness in this study
Documenting processes of data collection and interpretation – audit trail (Riessman, 2008)	√	Reflexive and methods logs Updates to supervisors Supervision records
Producing detailed transcripts (Riessman, 2008)	√	Interviews were recorded and transcribed verbatim.
Attention to language and contexts of production (Riessman, 2008)	√	Language – discourse of survivorship. Contexts of production – working within the three-dimensional narrative space emphasises the importance of interaction, continuity and situation. Narratives have been interpreted with reference to wider life context and socio-demographic and cancer-related variables. Where quotes have been presented, I have tried to include the question posed or background to the response so the quote can be judged within the context it was presented.
Acknowledgement of the ‘dialogic nature of narrative’ (Riessman, 2008)	√	I have taken the approach that the interview interaction is inherently ‘active’. Consideration has been given to the interview interaction and the influence I have had on stories told (See Chapter 10: Strengths and limitations).
A comparative approach – exploring similarities and differences between stories (Riessman, 2008)	√	See Chapter 5. Multiple-case analysis. Cross-case analysis to explore commonalities and differences across case. Merging case findings. Categorical aggregation.
Peer debriefing - which ‘provides an external check on the inquiry process’ (Lincoln and Guba, 1985: 301)	√	Supervision meetings Discussions with fellow researchers working in the field. Reflexive and methods logs
Negative/deviant case analysis (Lincoln and Guba 1985, Silverman 2010)	√	Deviant cases, i.e. cases that do not seem to fit a particular pattern, have been highlighted and discussed in the findings chapters e.g. Andy was the only long-term survivor who engaged in destructive behaviours post-treatment.
Member checking – testing the findings with those who were studied (Lincoln and Guba 1985, Stake 2006, Silverman 2010)	x	See p.346

Lincoln and Guba (1985) claim member checking is crucial to establishing credibility. However, I argue that there are multiple versions of reality. Therefore, it stands to reason that we will all interpret experiences differently, which could result in disagreements between participants and researchers regarding interpretations of participants' accounts. Lincoln and Guba do state 'clearly the investigator is not bound to honour all the criticisms that are mounted, but he or she is bound to hear them and weight their meaningfulness' (1985: 315). However, they do not elaborate *how* they would do this, and I question how ethical it is to disregard some comments but not others. Another issue is how we decide which participants to include in the member checking exercise? If we do not consult all participants do we not run the risk of providing a particular perspective on the findings? Based on these concerns, I decided not to engage in member-checking.

Theoretical openness

I established the philosophical and methodological underpinnings of my research at the outset. I have taken a subtle realist approach that shares with realism the idea that there is a reality independent of our beliefs and understandings about it but, simultaneously, shares with constructionism the idea that all knowledge is a human construction and, therefore, there are multiple realities (Hammersley 1992, Hammersley 2002). I also made clear the theoretical perspective adopted in the study. Chapter 4 outlines the theory of liminality, and my rationale for exploring its applicability with respect to long-term cancer survivorship. I sought to describe experiences of long-term survivorship at the individual and aggregate level *prior* to exploring the utility of liminality as an explanatory framework. However, I do acknowledge that it is impossible to completely set aside knowledge of the theory when interpreting participants' cancer narratives. It has been during the discussion that the utility of liminality has been explored. Recommendations for development of the theory are underpinned by research evidence presented in this thesis.

Awareness of the social setting of the research

As already touched on, cancer narratives were co-constructed in the interview interaction. In the section below on the study's strengths and limitations, I have outlined some thoughts on the data collection and analysis processes. Examples include how I feel my personal biography influenced the stories told, in terms of the questions I posed, the responses participants gave, and my interpretation of individuals' stories. I have also explored my professional background and how that may, or may not, have influenced the stories told, particularly if participants were aware that I am a social scientist, not a healthcare professional.

Awareness of the wider social context

I openly acknowledge the sources of funding that have made this research possible - the Economic and Social Research Council (ESRC) and Macmillan Cancer Support. To fund the study, the topic had to be of relevance to both organisations. The ESRC funds research covering a broad range of economic and social issues and Macmillan Cancer Support is a voluntary organisation that aims to improve the lives of everyone living with cancer through providing information and support, and campaigning for better cancer care. This being said, I have been able to steer the direction of the study based on my own research interests, and wider policy and research context. The rationale for the study stems from the fact that 'survivorship' is currently high on the health service and policy agenda, driven by the ongoing work of the National Cancer Survivorship Initiative. In addition, as highlighted in Chapter 3, relatively little research has been conducted on experiences of long-term cancer survivorship. With more people surviving cancer, and for longer - some with long-term and late effects of treatment - exploring individuals' experiences during this phase of the survivorship trajectory is pertinent, and timely.

Study strengths and limitations

Building on the account of reflexive awareness, I reflect here on the strengths of the research, as well as some of the limitations of the study design.

Did the study design fit the aims and objectives?

The strength of this exploratory study was the study design itself. The overall aim was to describe, and further understanding of, the experience of long-term survivorship. To highlight the appropriateness of the study design, I refer back to the characteristics of narrative and case study research (Table 10.2; see also Chapter 5 - Methods).

Table 10.2: Characteristics of narrative and case study research

Characteristics	Narrative Research		Case Study Research	
Focus	Exploring the life of an individual	√	Developing an in-depth description of a case or multiple cases	√
Type of problem suited to	Telling stories of individual experiences	√	Providing an in-depth understanding of a case or cases	√
Unit of analysis	One or more individuals	√	Studying an event, a program, an activity, more than one individual	√
Data collection	Interviews (and documents)	√	Multiple sources, such as interviews, observation, etc.	√
Data analysis strategies	Analysing data from stories, 'restorying', developing themes	√	Analysing data through description of the case and themes within the case, as well as cross-case themes	√
Report	A narrative about stories of an individual's life	√	A detailed analysis of one or more cases	√

(Source: Creswell, 2007: 78-79)

As documented, there has been a rise in the use of narrative as a method of data collection to explore the illness experience (Elliott 2005). Narrative allows

participants to tell us about their lives and the context within which they are lived (Phoenix 2008). Bury (1982) describes illness as a disruption. As such, narrative allows individuals to articulate that disruption, search for meaning in the illness experience and highlight actions taken to deal with the disruption – what this study sought to explore. I have touched on the debate regarding the rise of illness narratives and sought to circumvent criticism regarding lack of methodological rigour and romanticism (Atkinson 1997, Atkinson 2010) by combining what Chase (2005) refers to as the authoritative and interactive voices. I have interpreted the stories told, not taken them at face-value, paying close attention to the importance of how social and cultural contexts shape the stories told.

The holistic-content approach (sometimes referred to as ‘case study’) focuses on the life story, or part of it (oral history). Experiences are interpreted within the context of other parts of the narrative (Lieblich *et al.* 1998). This approach fits well with Clandinin and Connelly’s (2000) three-dimensional narrative inquiry space, which encourages researchers to explore the interaction, continuity and situation of narrative – social and personal relationships, the linkages between past, present and future experiences and place – all of which shape the story told. As I was particularly interested in developing in-depth (‘restoried’) accounts of participants’ experiences, working within the three-dimensional narrative inquiry space and adopting a holistic-content approach, facilitated the analysis. Adopting one of Stake’s (2006) approaches to cross-case analysis - merging case findings - allowed me to aggregate the individual stories and focus on the ‘quintain’ (experiences of long-term cancer survivorship as a whole), whilst maintaining the context of the individual ‘restoried’ accounts.

Data collection 1: Case selection

Thirteen people living long-term after a cancer diagnosis and eight ‘significant others’ were recruited to the study. This amounted to thirty individual interviews

and one joint interview. A recent review paper by Baker and Edwards (2012) posed the question: 'how many qualitative interviews is enough?' They asked a range of 'expert voices' to comment and the conclusion was 'it depends'. They considered *what* 'it depends' upon and suggested consideration of epistemological, methodological and practical issues was important (Baker and Edwards 2012). This exploratory study aimed to provide 'richness, complexity and detail' (Mason, 2012: 29 cited in Baker and Edwards, 2012) in order to describe the experience of long-term cancer survivorship. Charmaz argues that the 'intense scrutiny' entailed in narrative inquiry leads to a smaller number of interviews (Charmaz, 2012: 22 cited in Baker and Edwards, 2012). In my ethics application I specified that I would develop between fifteen and twenty cases. However, as I developed the 'restoried' accounts, I felt I had sufficient data when I reached thirteen cases. Any more and I would not have been able to do justice to the accounts shared. Indeed, Jensen suggested in Baker and Edwards' (2012) paper that when thinking about the size of the sample, consideration needs to be given to the researcher's ability to write up the interviews with 'dignity and care', something I was very conscious of. Essentially, I had to balance the methodological requirement and ethical obligation to produce in-depth, rich accounts with the practicalities of my thesis word count.

I wanted to ensure a mix of common and less common cancers in the study. However, most of the cases were from the three main cancer types, on which the majority of existing psycho-oncology research is based: breast, prostate and colorectal cancers. Nobody diagnosed with bladder cancer or Hodgkin's Lymphoma came forward as I had initially envisaged and more women than men came forward to take part in the study. Again, this is reflective of psycho-oncology research more widely (Fleer *et al.* 2006). There was also a lack of ethnic and socioeconomic diversity – something I highlighted as a limitation to existing survivorship research in Chapter 3. I had considered this in my recruitment strategy, initially planning to recruit in four London boroughs with varying levels of deprivation and ethnic diversity. However, I was relying on participant self-selection into the study and

may not have effectively targeted local community groups to recruit ethnic minority groups and those in lower socioeconomic groups.

The majority of participants were active in what Moira referred to as the cancer '*world*'. The study did not include any individuals diagnosed with prostate or colorectal cancer who were not involved with cancer charities in some way, so heterogeneity was also lacking in this respect. As a result, the survivors in this study may have offered views and opinions on the cancer '*world*' that differ to those not still engaged in it. I considered ways of accessing individuals who did not attend local cancer support groups, or volunteer/fundraise for cancer charities in the recruitment strategy. It was hoped that approaching a wide range of community groups would go some way to addressing this. However, although a small number of participants were recruited via non-cancer routes, the majority did stem from cancer-related organisations/groups. Where possible, the analysis has compared and contrasted experiences based on those who are still active in the cancer '*world*', those who are no longer involved in cancer-related activities and those who have never been involved.

Whilst the sample was homogeneous in terms of certain socio-demographic and cancer characteristics, it was heterogeneous with respect to age, employment status, cancer treatments received and time since treatment completion. Potential differences in experience as a result of these characteristics have been explored in the analysis. This being said, the homogeneity of the sample has implications for the assertions that can be made. Whilst I cannot say that findings are generalisable and, in any case, this is not the purpose of case study research, what I can say is that the study represents a stepping stone to further research into the experiences of individuals and their loved ones living long-term after a cancer diagnosis – a population that is yet to be researched widely in the UK. The size and homogeneity of the sample also poses questions regarding the suitability of the recruitment

strategy adopted. Next I discuss the limitations of my chosen recruitment strategy and present suggestions to overcome these in future research.

Data collection 2: Advantages and disadvantages of the recruitment strategy

Advantages to the strategies adopted included the few cost implications involved, and that those who came forward were interested in the topic and therefore willing, and able, to share their experiences (an important factor when conducting narrative interviews). Posting online meant a large number of individuals would see details about the study, in a short timeframe, and would be able to contact me quickly, in a relatively anonymous way, via email. Whilst posting the flyer on charity websites/forums was the most successful recruitment strategy, sharing information via gatekeepers was also important, as it meant those without access to the internet would hear about the study.

The overall disadvantage of the recruitment strategy was that accessing 'healthy volunteers' involved self-selection by participants into the study. As already discussed, those that registered their interest were, in the main, active in the cancer community and wanted to share their experiences. It could be said that they had a particular perspective on the cancer experience, which may have influenced certain findings. For example, evidence of 'communitas' was reported. This may not have been so evident had the majority of participants not been involved with cancer charities.

In addition, I was trying to recruit a relatively dispersed population – many of whom may not be involved with charities or local support groups anymore. Therefore, those that did come forward probably had ongoing needs/concerns or motivations for participating in the study. Also, those who are part of community groups are people who are generally mobile and able and participate in such activities. This might not be the case for older people, or those with physical limitations.

Therefore, by approaching cancer charities and local community groups, I was narrowing my potential sample to those who were active in their community or cancer '*world*', thus excluding so-called '*silent*' groups from the study.

Gaining access to community groups and local support groups was challenging. I distributed flyers and made calls but got little response. I was dependent on local groups regarding their capacity and/or desire to make people aware of the study. Anecdotal evidence from some cancer charities suggests that they receive many approaches for research support and therefore cannot accommodate all such requests. The same goes for putting up flyers on community notice boards, etc. – often there is no room so organisations have to prioritise requests. Once I had gained access, it was generally up to a gatekeeper to share information with individuals. I had no way of checking whether they had actually contacted individuals, what information they shared and with whom. I was reliant on them to actively recruit on my behalf and this was actually one of the least successful recruitment strategies. I acknowledge that there is greater scope for engaging with gatekeepers at local cancer support groups and local community groups. It would have been useful to attend community group meetings to give a short presentation on the research, but to do so required an initial response from local groups, which was often not forthcoming.

Based on these limitations, alternative recruitment routes may have been more appropriate. For example, I considered advertising in the local press. However, after conducting a risk assessment, my supervisors and I decided against this approach as it would not have been possible to vet those taking part. More often than not, I approached cancer charities and local support groups via a gatekeeper (for example, a '*Voices*' coordinator, support group Chair, etc.) who was able to confirm the legitimacy of potential participants. This approach acted as a safeguard for me in my capacity as a lone researcher.

An avenue explored during the development of the study was recruitment via GPs. There are examples of successful recruitment via GPs in the literature, for example, Harrison *et al.* (2011). Whilst recruitment via the NHS can be time-consuming and problematic (see also Table 5.2, p.136), it could potentially facilitate access to a larger pool from which to purposively select cases. In particular, recruitment via GPs may enable access to more 'silent' groups, such as those diagnosed with less common cancers, men, individuals from ethnic minority and lower socioeconomic status groups and those who do not, or cannot, participate in community life. Also, people may be more inclined to participate if the study has been endorsed by their GP.

Data collection 3: 'Identity matching' in interviews

During the interviews I was aware of the fact that participants may mediate what they share, in part as a result of my personal biography. Essentially, who I am influences the story told. I therefore considered whether 'identity matching' is useful in qualitative research. There is an argument that ensuring the researcher and participant are 'matched' on key socio-demographic criteria is helpful to the interview interaction (Lewis 2003). Lewis highlights that this issue has been raised in relation to matching on gender, stating that 'sharing some aspects of cultural background or experience may be helpful in enriching researchers' understanding of participants' accounts.' (2003: 65). However, a disadvantage to matching is that 'insufficient explanation or clarification is sought by the researcher because of assumptions created by their shared experience' (2003: 66). The same could be said of the participant. Participants might also find it helpful, or easier, to speak to someone outside their own social group. Janet said she felt she could speak more openly with me than her family because I had not been through the cancer experience with them. Lewis (2003) says it is important to weigh up the risks of identity matching versus not, but that 'ultimately, matching is no substitute for developing high quality fieldwork skills, having empathy and respect for

participants, being reflective about participants' social worlds as well as one's own, and being able to listen and understand' (2003: 66).

In most cases, identity matching was not possible in my area of research. However, I thought about some of the areas where my personal biography may have impacted on the story told, including my gender, age, professional background and the fact that I have not had cancer. The area I struggled most with was that I am not a nurse. However, I found that if participants knew I was not a nurse, they were more explicit about their experiences. Indeed, '...participants slant or edit their responses, often in ways that they believe will make sense to the researcher' (Underwood *et al.*, 2010: 1585). Participants may have assumed I knew little about the cancer experience within the NHS, the types of treatment they received, potential side effects, etc. or felt able to voice their concerns about care within the NHS as I was not a healthcare professional and therefore not directly influencing their care. However, I do acknowledge that some participants may have felt I would not understand their experiences because I did not have a medical background or know the workings of the NHS. Overall though, I found the former to be true – that participants were actually more open, and described their experiences in more depth, because I was *not* a nurse.

Data collection 4: Location of interviews

Based on a risk assessment, School of Health Sciences guidance on lone working and discussions with my supervisors, where possible, I conducted interviews in public places. This is in contrast to much research conducted in this field, where interviews are often conducted in the home. Drawing on the literature, as well as my own experiences, here I discuss the advantages and disadvantages of conducting interviews in the home, and what I would do differently in future research.

Conducting an interview in the home is convenient for the participant. They do not have to travel, which is particularly relevant for those with mobility issues. Atkinson (1998) suggests that the home might be the most appropriate setting as it provides a relaxed, comfortable setting that the interviewee is used to. Interviews in the home are also not necessarily bound to a set time frame. For example, if I have booked a meeting room or am interviewing someone at work I may only have a certain time within which to conduct the interview. Bergen (1993) suggests interviews in the privacy of the home are important to establishing the relationship between participant and researcher. Participants feel comfortable and in control of the situation. They determine the rules of the interaction e.g. where in the home the interview takes place. Being in the home, Bergen witnessed women speaking freely about their families, showing photos, etc. (as did Richard in my study). In this respect, details emerged that might not have been discussed otherwise (Bergen 1993).

As already alluded to, the main disadvantage to conducting interviews in the home is with regard to researcher safety. Walls *et al.* (2010: 31) argue that 'the nature of one-off interviews is that the researcher has no prior knowledge of the participants against which to judge whether or not to feel threatened or concerned by the prospect of interviewing in private...' They decided at the outset that the researcher would 'negotiate for a mutually agreed location, in a public area, where privacy and confidentiality was possible and [they] could summon help easily if necessary' (2010: 31). Paterson *et al.* (1999) also cite researcher safety as a methodological concern. They argue that it is not just the participant, but other people in the house, who could pose a risk (Paterson *et al.* 1999). For example, in my study, I interviewed Richard in his home. Whilst there, his son and his wife popped in. Whilst a gatekeeper vouched for this study participant, they could not account for other people entering the home. Aside from safety issues, it could also be argued that conducting an interview in the home could be distressing for the participant. We cannot assume that everyone would want to conduct an interview on a

sensitive topic in their own home, as it is their safe space or sanctuary. This space could be violated if the interview is distressing.

In future research I would establish where participants would prefer to be interviewed. If they were recruited via a gatekeeper, I would feel confident to interview them in their home if they wanted to, subject to an established safety protocol. If I were to recruit through newspaper advertising or GPs, I would still prefer to interview people in public places to ensure my safety.

Data analysis and presentation of findings

Case study research focuses on depth of understanding and complexity in specific contexts. However, one of my concerns was maintaining confidentiality and anonymity. I wanted to write up the cases as embedded case studies (Yin 2003), which include more than one unit of analysis (in this study: the person diagnosed with cancer and their 'significant other'). However, in one of my first interviews, the participant asked specifically if their account would be kept separate from that of their 'significant other', should they decide to participate. The participant shared personal details that could be distressing to their loved ones and I felt that they would not have nominated a 'significant other' had their stories been merged into one case. Therefore, from the outset, I was concerned about writing up the cases as embedded case studies.

Kaiser (2009) states that 'qualitative researchers face a conflict between conveying detailed, accurate accounts of the social world and protecting the identities of the individuals who participated in the research' (2009: 1632). Issues of anonymity are particularly relevant in 'dyadic' inquiry. Confidentiality is threatened when interviews may reveal details between the pair that were previously secret (Allmark *et al.* 2009). This creates issues in the write-up and use of quotes - whilst individuals

may not be identifiable to the general public, they may be identifiable to peers (Allmark *et al.* 2009).

Forbat and Henderson (2003: 1453) 'saw the desire to understand the relationship from both sides to outweigh the perils in accessing both stories but only when the ethical and procedural elements had been sufficiently worked through'. For example, they held discussions about confidentiality during recruitment, and at the beginning and end of interview and asked whether participants wanted to view their transcripts. They also assured participants that their account would not be shared with their partner. If the participant discussed the interview with their partner, that was their choice but the researcher did not comment on these accounts, for example, they did not answer questions like "did he/she tell you...?" Forbat and Henderson (2003) did acknowledge that it is more challenging dealing with information from one partner not mentioned by the other. In these cases they decided not to pursue it with the other partner, even if it was an interesting line of enquiry. The researcher decided that if the story was considered important to the other, they would mention it themselves. They acknowledged that potential data could be lost – but by adopting this approach they were 'maintaining an ethically defensible position' (2003: 1460). I took this approach in my study and feel ethically and morally at ease for doing so.

Based on my experiences, when conducting case-study research or in-depth, holistic analyses, a more detailed discussion of informed consent is required. This involves careful consideration of issues pertaining to anonymity and confidentiality, as well as ways to minimise distress – not just to the person taking part, but also to those close to them.

Several researchers have proposed a model of continuous informed consent (Richards and Schwartz 2002, Forbat and Henderson 2003, Allmark *et al.* 2009, Kaiser 2009) where the researcher reaffirms consent as part of an 'ongoing process

rather than a one-off event' (Richards and Schwartz, 2002: 137). However, participants should also be made aware that it might not be possible to ensure complete confidentiality, particularly with narratives and life stories, even when pseudonyms are used (Allmark *et al.* 2009).

Intrinsically linked to issues of maintaining anonymity and confidentiality is how researchers minimise distress that may be caused during the course of research. This includes distress that may be felt by the participant in the interview itself, but also distress felt by others, for example, a 'significant other' reading something about their partner that they found upsetting. It was the latter scenario that was of concern to me when considering how to write up the case studies. Unstructured interviews provide participants with considerable control, but this creates a different 'risk profile' (Corbin and Morse 2003). Johnson & Macleod-Clarke (2003) suggest that in terms of the costs of involvement in research, the definition of 'sensitive' should move beyond the obvious i.e. topics that have potential to generate an emotional response, to include topics in which the outcome may have social implications (2003: 421) i.e. socially sensitive topics. In this sense we need to think about the threat or 'cost' of participation, not just to the individual participant, but those in their wider social sphere as well.

On the flip side is the positive impact participating in research can have. Corbin and Morse (2003) acknowledge that interviews may cause emotional distress but that there is no indication that this distress is any greater than in everyday life. Johnson and Macleod Clarke's general opinion is that benefits outweigh costs, but the issue is that a researcher cannot always be certain about the impact - what may benefit one, may harm another. This goes for the participants themselves, and their wider social spheres.

Participating in research may have a therapeutic effect as it can help participants find meaning in the experience (Clark 2010). For some people, an interview is their

first opportunity to discuss the issue and even though it might be difficult it can also be therapeutic to 'get it off their chest' (Walls *et al.* 2010). It is often an opportunity to focus on the subject, something that the participant might not have been able to do before or something they felt they could not do with friends and family. For example, in this study, Janet appreciated being able to talk about her experiences with someone who was not personally involved in her cancer story. This allowed her to talk through some of her feelings and actually gave her hope for the future. Research gives people a chance to talk about painful experiences in a controlled environment, with an informed researcher (Dyregov 2004). Indeed, 'attention from a researcher may act as validation' of the participant's ongoing concerns (Grinyer, 2004: 1341).

A strong motive for participating in qualitative research, even if it might be distressing, is altruism - that one's story might help others (Bergen 1993, Dyregov 2004, Grinyer 2004, Peel *et al.* 2006, Carter *et al.* 2008). This was a common reason amongst the participants in this study (and could stem from the fact that many of them were still actively engaged with cancer charities). Clark (2010) also suggests that at a 'collective' level, a reason for participation in research is to inform 'change'. This is an important consideration in the cancer context: 'another driving role of engagement is the hope that the research will be useful in informing some area of policy or professional practice that will change the social experience of people perceived to be in similar contexts' (Clark, 2010: 413). For example, in this study Richard campaigns for a more accurate screening tool than the PSA test for prostate cancer as he wants to help save lives. Engagement is driven by the 'perceived positive contribution that their involvement will have to other members of similar collective groups' (2010: 413). Likewise, Carter *et al.* (2008: 1264) report that the purpose of participation in research is to 'assist the communities to which one belonged'.

Ultimately, considering issues of maintaining anonymity and confidentiality and minimising distress caused to participants and those close to them, alongside some of the reasons why participants decided to take part in this study, I felt I could not write the cases as embedded case studies as the interviews with those who had been diagnosed with cancer and their 'significant others' were conducted separately. Instead, I conducted a thematic analysis of the 'significant other' data and reported these findings separately. With hindsight, had I conducted joint interviews, it would have been easier to report findings as embedded case studies, although joint interviews come with their own set of disadvantages (See Table 5.3, p. 147). Adopting this approach ensured that I could write in-depth accounts of participants' experiences, and report the overarching perspectives of 'significant others', whilst protecting the anonymity of all those involved. Through this approach I could do justice to all the accounts, giving both those diagnosed with cancer and their 'significant others' a voice and hopefully enabling them to fulfil their desire to help other people affected by the disease.

The final chapter, Conclusions, highlights this study's contribution to the evidence base, and discusses the implications of the findings for theory, society, practice and research.

Chapter 11. Conclusions

Introduction

As more people are surviving cancer, and for longer, cancer survivorship is a key clinical, policy and research issue, but also one that has implications for wider society. As such, this exploratory study aimed to describe and further our understanding of the experience of cancer in the long-term survivorship phase (≥ 5 years post-treatment).

Through the 'restorying' of individual narrative accounts and a cross-case analysis, I described individual and collective experiences of long-term cancer survivorship. Through a series of in-depth case studies I highlighted the impact of cancer on daily living, self, outlook on life and relationships. The subsequent cross-case analysis drew attention to the simultaneous benefits and losses experienced during long-term survivorship. I developed a typology of the place of cancer (*'past', 'past-present' and 'present-future'*) which is underpinned by a legacy of *lingering uncertainty*. The dynamism and fragility of the place of cancer was also highlighted. It oscillates between the foreground and background of participants' lives, and between the past, present and future, as a result of varied manifestations of lingering uncertainty and *'reality checks'* experienced during this phase of the survivorship trajectory. Tentative explanations for the place of cancer in individuals' lives at the time of interview were explored with reference to socio-demographic, cancer-related and wider life and health contexts.

Here I discuss the implications of the findings, and conclude by highlighting the contribution this study makes to the cancer survivorship evidence base.

Theoretical implications

In Chapter 3 I highlighted that theoretical frameworks have rarely underpinned studies on long-term cancer survivorship. One of the arguments against the use of theory in qualitative research is that researchers force the data into pre-existing categories. However, if categories are 'critically interrogated throughout the research process' it can lead to 'intellectual gains' for qualitative health research (MacFarlane and O'Reilly-de Brun, 2012: 616). This study was interested in exploring the utility of liminality as a framework for understanding experiences of long-term cancer survivorship. My initial 'critical interrogation' of the theory was through a literature review (Chapter 4), which highlighted that whilst the theory may be pertinent to our understanding of living *with* and *through* cancer, gaps in the evidence base meant it was unclear whether the same was true for living *beyond* cancer i.e. long-term cancer survivorship. As such, my research objectives focused on critically analysing the utility of liminality as a means of understanding long-term survivorship.

I explored liminality specifically with respect to those living long-term after a cancer diagnosis, which has not been undertaken before. I suggest that most, but crucially not all, individuals living long-term after a cancer diagnosis live in a state of 'sustained' liminality. As such, liminality is not permanent for all, as has been suggested by Little *et al.* (1998). Those for whom cancer is in the 'past' have transitioned out of this state and successfully reincorporated into a new state of 'health' or 'wellness'. They have experienced growth as a result of the cancer experience, which can be interpreted as reincorporating into a higher state of consciousness. I suggest that gaining closure is key to transitioning out of the liminal state, presenting examples of participants who have gained closure and how this was achieved. My conceptualisation of 'sustained' liminality focuses on the *physical* liminality experienced as a result of ongoing consequences of cancer treatment (surviving the experience of cancer) and *existential* liminality felt as a result of an

ongoing fear of recurrence (surviving the disease). Some of the participants in the 'past-present' and 'present-future' groups have also experienced something akin to post-traumatic transformation (Kahana *et al.* 2011), adding weight to the argument that living a liminal life can have generative and transformative potential (Turner 1967, Turner 1969, Thompson 2007). I argue that this growth can often occur simultaneously alongside the negative consequences of cancer and its treatment.

Therefore, findings suggest that liminality is a pertinent framework to facilitate our understanding of the experience of long-term survivorship, but offer insights beyond Little *et al.*'s (1998) conceptualisation of liminality. As such, the findings presented here add to the theoretical discussion regarding liminality and the cancer experience – a so-called 'intellectual gain' for qualitative health research (MacFarlane and O'Reilly-de Brun 2012).

Societal implications

This study has raised questions about how we refer to people who have been affected by cancer. In the UK, 'survivorship' rhetoric has been adopted from North America and is used by policy makers, researchers, healthcare professionals, the media, and charities. However, the terminology is not universally accepted. Indeed, whilst the majority of participants in this study acknowledge and accept the terminology used to describe them, they do not identify with the term personally and have not internalised the 'survivor' identity into their self-concept. Whilst they may literally be a 'cancer survivor', most do not refer to, or perceive, themselves as such. This being said, the term does resonate with a minority. The 'survivor' identity is integrated into their self-concept and reflects how they want to be perceived by others. Therefore, being labelled a 'survivor' has positive connotations for these individuals. It seems that we need to move past meta-narratives of 'survivorship', 'fighting', engaging in a 'war' or 'battle', etc. because they do not always resonate with those who have been affected by the disease. For

example, Khan *et al.* (2012) suggest we move away from the term ‘cancer survivor’ and use more descriptive terminology to describe the population of people who have been diagnosed.

Illness has a social, as well as personal, dimension. It is possible wider society identifies with terms like ‘cancer survivor’ because it implies something positive. McKenzie (2004: 108) describes a ‘climate of fear’ about cancer. The idea of ‘survivorship’ moves those diagnosed with cancer away from being the ‘omens of hazard’ (McKenzie and Crouch 2004) they once were. Family and friends want to forget that they have been made ‘death salient’ (Little and Sayers 2004a) – survivorship rhetoric helps them do that. However, for the ‘survivors’ this may imply they are ‘back to normal’. They may not feel that way but conceal their fears and concerns for the benefit of others. This can lead to isolation, as those affected by cancer cannot share in the ‘practical consciousness of a taken-for-granted, future-orientated world view’ (McKenzie, 2004: 120).

I conclude that further consideration of ‘cancer survivorship’ rhetoric, which is fast becoming embedded within society, is necessary as the terminology used is often not acceptable to those it refers. However, as Malcolm implied, it will be impossible to get it right for everyone:

Malcolm (first interview): ...there is no commonality of language at all. And the debate we’ve had over the last 3 years about ‘survivorship’ or ‘living with’ now, none of them are suitable, but I don’t know which one I would prefer... Nothing’s going to be easy and nothing’s going to be right.

Implications for practice

I have positioned the implications for practice within the emerging framework of ‘aftercare’ services being developed through the work of the National Cancer

Survivorship Initiative (NCSI) in England, as well as wider policy and service developments taking place in North America. There is a move from a 'one-size fits all' approach to clinical follow-up (focusing on surveillance and detecting recurrence) to a more personalised, tailored, risk-stratified 'aftercare'. The NCSI's vision is that individuals receive the care and support they need to lead healthy and active lives for as long as possible (Department-of-Health 2010). In England, through risk stratification and holistic needs assessments, healthcare professionals and the individual diagnosed will work together to identify the most appropriate aftercare for that individual. The aim is to encourage those at low risk of recurrence to self-manage – providing them with information, support and skills to look after their own health and wellbeing, as well as identifying a key worker within the NHS whom they can contact should they need to.

Whilst some participants have adjusted well to life post-treatment, others have ongoing problems and concerns that impact physical functioning and, therefore, daily life. This finding is supported by previous research, where the consensus is that approximately 20-30% of long-term survivors experience ongoing issues (Deimling *et al.* 2006a, Armes *et al.* 2009a, Foster *et al.* 2009, Harrison *et al.* 2011). The key challenges are identifying the individuals who require ongoing support, and identifying and implementing the most effective interventions to meet their needs. The NCSI proposes that survivors and their GPs will be provided with a treatment summary and survivorship care plan, which outline treatments received, the risk of late effects of treatment and follow-up care needs. The aim of these tools is to improve communication and coordinate care between hospital oncology services, primary care and cancer survivors (Figure 11.1).

Figure 11.1: Treatment summaries and survivorship care plans

Treatment summary: aim to develop communication and collaboration between hospital cancer services and primary care. Primary care providers need to be aware of potential late effects for those with a history of cancer. For example, if a survivor presents with a new symptom, the GP should consider whether it might be related to the cancer diagnosis (Burton 2010). The treatment summary should be completed by the hospital at the end of treatment, with copies sent to the survivor and their GP.

Survivorship Care Plans (SCP): aim to outline treatments received, the risk of late effects of treatment and follow-up care needs (Hewitt *et al.* 2005). It should also include ongoing treatments, treatment complications experienced and contact information for members of the multi-disciplinary team (MDT) (Phillips and Currow 2010). The treatment summary forms one part of the SCP (Watson *et al.* 2011).

The following sections discuss what holistic needs assessments should cover, when they should take place, who should be involved in the assessment and some of the information and support needs, highlighted by participants in this study, that healthcare professionals should be cognizant of during this phase of survivorship.

Holistic needs assessment: what should it cover?

Any assessment should look holistically at the individual's needs. Healthcare providers need to understand what else is happening in their wider life, as well as their cancer-related concerns. Consideration should be given to what other health conditions individuals are living with. Have they attributed meaning to the illness i.e. found an explanation as to why they developed cancer, or are they still grappling with the meaning of cancer? Placing cancer within the context of the individual's wider life and life stage will help healthcare professionals understand their ongoing issues and, importantly, their implications for daily functioning, their self-concept, relationships, etc., so that appropriate advice and support can be offered. Not only is it important to outline the possible late effects of treatment,

but also explore the meaning/implications of those side effects for those who may experience them. Essentially, holistic needs assessments should ensure supportive care is tailored to the individual.

Holistic needs assessments: when?

Boyd and Murray (2010) discussed the importance of recognising key transitions in end of life care. They argue that we can ascertain when someone will benefit from supportive care if we identify key transition points (Boyd and Scott 2010). Building on their premise, a useful approach may be to identify the transition points within an individual's survivorship trajectory. The end of treatment is one key transition point. A holistic needs assessment should take place at this point and, if appropriate, individuals should be provided with, or signposted to, tailored information and support. Assessment at this point might help them as they move into long-term survivorship. For example, several participants in this study were still unsure of signs and symptoms of recurrence. As a result, they continue to live with a sense of lingering uncertainty many years after treatment completion.

I would suggest that another assessment should take place around the five-year survival marker. Reaching the five-year point is instrumental in helping some individuals draw a line under the cancer experience and gain closure. However, others struggle when they are discharged from follow-up. As Andy's wife Rachel said, the '*security blanket*' had been taken away – so individuals may need additional support at this point. In this study, participants want to feel they can contact relevant health professionals if needed, but in the main want to manage the consequences of cancer treatment themselves. For example, Richard has a supportive GP who prescribes him a supply of antibiotics so that he can treat infections caused by self-catheterisation himself.

Holistic needs assessments: By whom?

Primary care is well placed to support those living with the consequences of cancer and its treatment because they already deliver some aspects of cancer care, for example, PSA monitoring and managing comorbidities. Watson *et al.* argue that GPs are 'experts at delivering longitudinal chronic disease management' (2011: 694). The Department of Health (England) requires all patients diagnosed with cancer to receive a Cancer Care Review (CCR) by their GP within six months of the GP receiving confirmation of their diagnosis. Watson *et al.* (2011) suggest that the current timing of the CCR should be supplemented by another appointment at the end of treatment. Based on the findings from this study, I would argue that a CCR should also take place at five years post-treatment. This would have benefited someone like Malcolm who felt abandoned at the five-year point, particularly as he had moved and consequently lost the relationship he had developed with his previous GP and hospital team.

Information and support needs during long-term cancer survivorship

Findings suggest that the majority of those living long-term after a cancer diagnosis have searched for a cause of their cancer, but often found it difficult to come up with an explanation. Participants with children talked about how they now know, or worry, that their children are at a higher risk of developing cancer because they were diagnosed. Cancers that may be caused by inherited faulty genes include breast, ovarian, colorectal and prostate cancer. However, only around 5% of cancers are caused by an inherited faulty gene³⁹. Therefore, this manifestation of lingering uncertainty might be quite simple to overcome if health professionals provide patients with information about the relative risk of familial cancer. This may

³⁹ <http://cancerhelp.cancerresearchuk.org/about-cancer/cancer-questions/are-all-cancers-hereditary> [Accessed April 26th 2012].

reduce worry and anxiety and, in some cases, guilt felt by some individuals that they are influencing their children's future health.

Some participants in this study talked about how they modified their lifestyles post-treatment to manage their risk, and fear, of recurrence. However, this was not always maintained into long-term survivorship. Evidence suggests that physical activity and a healthy diet can prevent recurrence (Davies *et al.* 2011) therefore those living long-term after cancer should be encouraged to maintain an active lifestyle. Davies *et al.* (2011) found that individuals want to take an active role in looking after themselves but the challenge is integrating lifestyle support and advice into models of aftercare. Lifestyle advice should also be part of the information and education delivered through self-management programmes, at the post-treatment review and again at the five-year point, perhaps as part of the CCR, so individuals feel confident that they are doing something to help manage their risk of recurrence.

Some participants described ongoing problems with sexual functioning. Consideration needs to be given to the way in which discussions about such a sensitive topic can be initiated, and by whom, as well as how to ensure individuals know they can approach health professionals about their concerns. For example, Kate is now six years post-treatment and does not know where to turn to discuss her relationship and intimacy concerns. Sexual issues should be 'normalised' through routine assessment and appropriate therapy recommended where necessary (Mah *et al.* 2011). However, to enable referral to additional support services, appropriate interventions need to be in place. Roger highlighted a need for support groups for gay men. Men need a safe and supportive environment to discuss the impact of treatment on sexual function (individual and couple-based), as well as a forum for providing information about the legalities of civil partnerships, next of kin, etc.

Attention to the uncertainty and contradiction inherent in living in a state of liminality (in-between health and illness) is an important consideration for health professionals, at all stages of the cancer trajectory. If those living five years or more post-treatment experience 'sustained' liminality, supportive care needs, encompassing physical and existential concerns, may be ongoing, and persist indefinitely. However, recognising and supporting the generative potential of 'sustained' liminality is also an important consideration.

Avenues for future research

Subtle realism points to the existence of 'situated truths' and multiple realities, which suggest that it is not possible to generalise findings from this study to the wider population of people living long-term after a cancer diagnosis. Also, as this study was exploratory in nature, the findings 'indicate rather than conclude' (Mason 2002). In effect, the findings and conclusions drawn here are my 'working position' and therefore need to be built upon to develop the body of evidence on experiences of long-term cancer survivorship. Case study research also does not aim to generalise but, if the reader relates to the case, this can be a natural basis for generalisation (Stake 1995, Stake 2006). In multiple-case studies, we are working with data at the aggregate level, looking for patterns of correspondence, which effectively means generalising within cases. An example within my study was the identification of the typology of the place of cancer in long-term survivorship. Further research is necessary to ascertain whether these findings hold true in similar, and contrasting, settings. Further exploration of interpersonal, intrapersonal and wider sociocultural contexts is also necessary to further our understanding of the dynamic place of cancer in long-term survivorship.

A prospective, longitudinal study exploring changes in experience over time would add to the evidence base, as there is a dearth of research exploring how the experience and meaning of cancer changes over time. My study retrospectively

explored individuals' experiences of diagnosis and treatment and other life events that have happened between diagnosis and the long-term survivorship phase. A prospective, longitudinal study would enable exploration of the meaning of events as they happen and then, later, exploration of how those meanings may have changed and why. It would be possible to explore the salience of the survivorship trajectory as outlined in Chapter 2. For example, longitudinal research could ascertain whether individuals move through the various stages (acute, transitional, extended and long-term) and when. It would also be interesting to explore how '*reality checks*' and manifestations of lingering uncertainty may fluctuate and change over time and thus influence the place of cancer in participants' lives. This approach would also help position the research within the three-dimensional narrative inquiry space. It would be possible to explore continuity (past-present-future experiences) in more depth, by comparing and contrasting the meaning of events as they happen (present), with the meaning ascribed to events experienced in the past and perceptions of the meaning of future experiences.

It would have been interesting to include individuals diagnosed with cancers that typically do not reach long-term survivorship, for example, lung and head and neck cancers. It would then be possible to explore experiences of long-term survivorship from the perspective of those who are not necessarily expected to reach that stage of survivorship, and compare experiences with those of individuals diagnosed with cancers that have better five-year survival rates. It would also have been interesting to explore the impact of head and neck cancer on identity, particularly body image, and the potential stigma associated with head and neck and lung cancers. Development of head and neck cancer is associated with alcohol consumption and smoking, whilst lung cancer is also linked with smoking – activities that are often perceived as socially unacceptable in terms of health maintenance. Therefore, individuals could be blamed for their cancer by wider society. However, as already mentioned, head and neck and lung cancer have low long-term survival rates. In

addition, head and neck cancer is a less common cancer, so recruitment would have been problematic using the strategies I employed.

A prospective, longitudinal study would also allow me to explore the theory of liminality across the cancer trajectory. I was looking for evidence of liminality during long-term cancer survivorship, but through the retrospective discussion of life following treatment there was evidence of 'communicative alienation', etc. during the transition phase of survivorship. Whilst 'communicative alienation' may not be as evident today, it likely to have shaped the cancer experience. As such, it seems important to explore potential changes in the liminal experience over time. For example, future research might explore when and how individuals move from a period of 'acute' liminality to the 'sustained' phase, and possibly beyond.

It would also be interesting to explore liminality from the perspective of 'significant others' – do they experience 'sustained' liminality and a sense of 'communicative alienation', 'boundedness' and 'cancer patientness'? Based on comments made by some of the individuals diagnosed with cancer and their 'significant others' in this study, I would suggest that they do. For example, Richard said that cancer is '*insidious*' and affects everyone around the individual diagnosed. Sheila, the wife of one of the participants, described a sense of 'boundedness' when discussing the fact that she would like to travel abroad, but that this is not possible due to the ongoing consequences of treatment her husband experiences. This led me to consider that 'significant others' are also on the margins or 'in limbo'. I identified one study in the cancer literature that explored the ambiguity and uncertainty felt by the male partners of women treated for breast cancer (Harrow *et al.* 2008). The study found that men's experience was characterised by a sense of ambiguity and uncertainty in terms of their role, their relationship with their partner and their ability to move on from breast cancer. Future studies might feature joint interviews with those diagnosed and 'significant others' to explore their experiences together.

Concluding remarks: contribution to the evidence base

This study has presented a narrative understanding of the experience of long-term cancer survivorship, complimenting the 'distress' focus of much psycho-oncology research. Adopting a holistic approach and positioning the study within the three-dimensional narrative inquiry space provided a novel methodological approach to exploring the illness experience. Fundamentally, the study emphasises the importance of positioning cancer within the context of participants' daily lives and the life course. Exploring the dynamic interplay between intrapersonal, interpersonal and societal factors has provided an enhanced understanding of the experience of long-term survivorship.

By defining 'long-term cancer survivors' as individuals who are at least five years post-treatment and conducting a study that focused specifically on this population, I have provided a degree of definitional clarity that is not always evident in survivorship research. The study also adds to the discussion regarding the term 'cancer survivorship' and adoption of the 'cancer survivor' identity. It therefore makes an important contribution to the debate on 'survivorship' rhetoric adopted in the UK, in particular, questioning how we refer to, and define, the population of people affected by cancer.

This study is one of only a small number of UK-based studies on the subjective cancer experience, and only one of two specifically on those five years or more post-diagnosis/treatment. With so little UK-based research on the experience of long-term survivorship, this study has laid the foundations for further exploration of the illness experience in this population. Some of the findings support the predominantly US-based research on survivorship. However, the study adds to the evidence base by highlighting the need to consider the variable extent of post-traumatic transformation experienced by those living long-term after a cancer diagnosis and the subsequent need to explore both positive and negative facets of

the cancer experience if we are to fully understand the experience of long-term cancer survivorship. I have also highlighted that a sense of lingering uncertainty persists into long-term survivorship, and that it manifests itself in different ways and to different extents from individual to individual. However, the main manifestation continues to be fear of recurrence. This finding is supported by recent research by the Department of Health in England that found 43% of respondents reported a fear of recurrence at five years post-diagnosis (Department-of-Health 2012).

Whilst previous research has highlighted some of the triggers or '*reality checks*' experienced by participants, this study reports that these '*reality checks*' cause the place of cancer to fluctuate between the background and foreground of individuals' lives. I also found that it is not just cancer-related events that cause this fluctuation, but life events as well. As such, I stress the importance of wider personal and social context when considering when and why the place of cancer fluctuates in individuals' lives. I developed a typology of the place of cancer in long-term survivorship, describing how cancer is in the 'past', 'past-present' or 'present-future'. I highlighted that the place of cancer is not static, but fragile and dynamic, oscillating between the past, present and future as a result of the lingering uncertainty and '*reality checks*' experienced by participants in this study. Whilst the typology resonates with Miller *et al.*'s (2008) model of survivorship, I argue that a new category is required, which accounts for those who are effectively 'disease-free' but live with an ongoing sense that cancer is still *within* them (the 'present-future' group).

The study also makes a theoretical contribution through an exploration of the applicability of liminality as a framework for understanding experiences of long-term cancer survivorship. Research on liminality and the experience of those specifically five years or more post-treatment had not previously been undertaken. Whilst the theory shows utility, suggestions for theory development have been

presented. This will hopefully enhance policymakers', researchers' and healthcare professionals' understanding of this phase of the survivorship trajectory, as well as being an 'intellectual gain' for qualitative health research more broadly.

Final thoughts

Stories, by their very nature, are unfinished. As such, I am left wondering "what happened next?" to those who participated in the study. I hope they gained as much from the experience as I did and that I have been able to do justice to their accounts. Through this and future studies, I hope we can begin to influence policy and practice to improve the lives of those living long-term after a cancer diagnosis.

References

- Alfano C. M., Day J. M., Katz M. L., Herndon J. E., 2nd, Bittoni M. A., Oliveri J. M., Donohue K. & Paskett E. D. (2009) Exercise and dietary change after diagnosis and cancer-related symptoms in long-term survivors of breast cancer. *Psycho Oncology* **18**, (2), 128-133.
- Allan H. (2007) Experiences of infertility: liminality and the role of the fertility clinic. *Nursing Inquiry* **14**, (2), 132-139.
- Allmark P., Boote J., Chambers E., Clarke A., McDonnell A., Thompson A. & Tod A. (2009) Ethical issues in the use of in-depth interviews: literature review and discussion. *Research Ethics Review* **5**, (2), 48-54.
- American-Cancer-Society (2012) Cancer treatment and survivorship facts and figures 2012-2013. Atlanta: American Cancer Society.
- Andrews M. (2008) Never the last word: revisiting data. In: *Doing Narrative Research*. Andrews, M., Squire, C. & Tamboukou, M. (Eds.), Sage: London, p. 86-101.
- Anspach R. (1993) *Deciding Who Lives: Fateful Choices in the Intensive-Care Nursery*. University of California Press: Berkeley and Los Angeles.
- Anspach R. & Mizrachi N. (2006) The field worker's fields: ethics, ethnography and medical sociology. *Sociology of Health & Illness* **28**, (6), 713-731.
- Armes J., Crowe M., Colbourne L., Morgan H., Murrells T., Oakley C., Palmer N., Ream E., Young A. & Richardson A. (2009a) Patients' supportive care needs beyond end of cancer treatment: a prospective, longitudinal survey. *Journal of Clinical Oncology* **27**, (36), 6172-6179.
- Armes J., Richardson A. & Addington-Hall J. (2009b) Determining Research Priorities for Cancer Survivorship: consultation and evidence review - Report on National Cancer Survivorship consultation on research priorities. University of Southampton and King's College London.
- Arrington M. I. (2003) "I don't want to be an artificial man": Narrative reconstruction of sexuality among prostate cancer survivors. *Sexuality & Culture: An Interdisciplinary Quarterly* **7**, (2), 30-58.
- Atkinson P. (1997) Narrative turn or blind alley? . *Qualitative Health Research* **7**, (3), 325-344.
- Atkinson P. (2010) The contested terrain of narrative analysis - an appreciative response. *Sociology of Health & Illness* **32**, (4), 661-662.
- Atkinson R. (1998) *The Life Story Interview*. Sage: Thousand Oaks.
- Aziz N. (2002) Cancer Survivorship Research: Challenge and Opportunity. *Journal of Nutrition* **132**, 3494S-3503S.
- Aziz N. M. (2007) Cancer survivorship research: state of knowledge, challenges and opportunities. *Acta Oncologica* **46**, (4), 417-432.
- Aziz N. M. (2009) Long-term cancer survivors: research issues and care needs in a key phase of the survivorship spectrum. *American Journal of Hematology* **84**, (12), 782-784.

- Baker S. E. & Edwards R. (2012) How many qualitative interviews is enough? Expert voices and early career reflections on sampling and cases in qualitative research. *National Centre for Research Methods Review Paper*. National Centre for Research Methods.
- Barnett-Page E. & Thomas J. (2009) Methods for the synthesis of qualitative research: a critical review. *BMC Medical Research Methodology* **9**, (59).
- Beckjord E., Arora N., McLaughlin W., Oakley-Girvan I., Hamilton A. & Hesse B. (2008) Health-related information needs in a large and diverse sample of adult cancer survivors: implications for cancer care. *Journal of Cancer Survivorship* **2**, 179-189.
- Bellizzi K. M. (2004) Expressions of generativity and posttraumatic growth in adult cancer survivors. *International Journal of Aging & Human Development* **58**, (4), 267-287.
- Bellury L. M., Ellington L., Beck S. L., Stein K., Pett M. & Clark J. (2011) Elderly cancer survivorship: an integrative review and conceptual framework. *European Journal of Oncology Nursing* **15**, (3), 233-242.
- Benton T. & Craib I. (2001) *Philosophy of Social Science: The Philosophical Foundations of Social Thought*. Palgrave: New York.
- Bergen R. (1993) Interviewing survivors of marital rape: doing feminist research on sensitive topics. In: *Researching sensitive topics*. Renzetti, C. & Lee, R. (Eds.), Sage: Newbury Park, p. 197-211.
- Bertero C. & Wilmoth M. C. (2007) Breast cancer diagnosis and its treatment affecting the self: a meta-synthesis. *Cancer Nursing* **30**, (3), 194-204.
- Bishop E. & Shepherd M. (2011) Ethical Reflections: Examining Reflexivity Through the Narrative Paradigm. *Qualitative Health Research* **21**, (9), 1283-1294.
- Bishop M., Curbow B., Springer S., Lee J. & Wingard J. R. (2011) Comparison of lasting life changes after cancer and BMT: perspectives of long-term survivors and spouses. *Psycho Oncology* **20**, 926-934.
- Blank T. O. (2009) Cancer from Both Sides Now: Combining Personal and Research Perspectives on Survivorship. *Journal of General Internal Medicine* **24**, 425-428.
- Bloom F. R. (1997) Searching for meaning in everyday life: Gay men negotiating selves in the HIV spectrum. *Ethos* **25**, (4), 454-479.
- Bloom J. (2002) Surviving and thriving? *Psycho Oncology* **11**, 89-92.
- Bloom J., Petersen D. & Kang S. (2007) Multi-dimensional quality of life among long-term (5+ years) adult cancer survivors. *Psycho Oncology* **16**, 691-706.
- Bowman K., Deimling G., Smerglia V., Sage P. & Kahana B. (2003) Appraisal of the cancer experience by older long-term survivors. *Psycho Oncology* **12**, (3), 226-238.
- Boyd K. & Scott S. (2010) Recognising and managing key transitions in end of life care. *BMJ* **341**, (c4863).
- Breaden K. (1997) Cancer and beyond: The question of survivorship. *Journal of Advanced Nursing* **26**, (5), 978-984.
- Bryman A. (1988) *Quantity and quality in social research*. Routledge: London.

- Bryman A. & Burgess R. (1994) Developments in qualitative data analysis: an introduction. In: *Analyzing qualitative data*. Bryman, A. & Burgess, R. (Eds.), Routledge: London & New York, p. 1-17.
- Burton C. (2010) The effects of surviving cancer. *GP Clinical*. Haymarket.
- Bury M. (1982) Chronic illness as biographical disruption. *Sociology of Health & Illness* **4**, (2), 167-182.
- Bury M. (2001) Illness narratives: fact or fiction? *Sociology of Health & Illness* **23**, (3), 263-285.
- Bussing A. & Fischer J. (2009) Interpretation of illness in cancer survivors is associated with health-related variables and adaptive coping styles. *BMC Women's Health* **9**, (2).
- Campbell H. S., Phaneuf M. R. & Deane K. (2004) Cancer peer support programs – do they work? *Patient Education & Counseling* **55**, 3-15.
- Carricaburu D. & Pierret J. (1995) From biographical disruption to biographical reinforcement: the case of HIV-positive men. *Sociology of Health & Illness* **17**, (1), 65-88.
- Carter B. J. (1993) Long-term survivors of breast cancer: a qualitative descriptive study. *Cancer Nursing* **16**, (5), 354-361.
- Carter S., Jordens C., McGrath C. & Little M. (2008) You have to make something of all that rubbish, do you? An empirical investigation of the social process of qualitative research. *Qualitative Health Research* **18**, (9), 1264-1276.
- Cayless S., Forbat L., Illingworth N., Hubbard G. & Kearney N. (2010) Men with prostate cancer over the first year of illness: their experiences as biographical disruption. *Supportive Care in Cancer* **18**, (1), 11-19.
- Cesario S. K., Nelson L. S., Broxson A. & Cesario A. L. (2010) Sword of Damocles Cutting Through the Life Stages of Women With Ovarian Cancer. *Oncology Nursing Forum* **37**, (5), 609-617.
- Charmaz K. (1983) Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health & Illness* **5**, (2), 168-195.
- Charmaz K. (1987) Struggling for a self: Identity levels of the chronically ill. *Research in the Sociology of Health Care* **6**, 283-321.
- Charmaz K. (1999) Stories of Suffering: Subjective Tales and Research Narratives. *Qualitative Health Research* **9**, (3), 362-382.
- Charmaz K. (2002) Stories and silences: disclosures and self in chronic illness. *Qualitative Inquiry* **8**, (3), 302-328.
- Chase S. (2005) Narrative Inquiry: Multiple Lenses, Approaches, Voices. In: *The Sage Handbook of Qualitative Research*. Denzin, N. & Lincoln, Y. (Eds.), Sage: London, p. 651-679. 3rd ed
- Clandinin D. & Connelly F. (2000) *Narrative inquiry: experience and story in qualitative research*. Jossey-Bass: San Francisco.
- Clark T. (2010) On 'being researched': why do people engage with qualitative research? *Qualitative Research* **10**, (4), 399-419.
- Clarke J. N. & Everest M. M. (2006) Cancer in the mass print media: fear, uncertainty and the medical model. *Social Science & Medicine* **62**, 2591-2600.

- Colyer H. (1996) Women's experience of living with cancer. *Journal of Advanced Nursing* **23**, (3), 496-501.
- Cooley C. (1964) *Human nature and the social order*. Schocken Books: New York.
- Corbin J. & Morse J. (2003) The unstructured interactive interview: issues of reciprocity and risks when dealing with sensitive topics. *Qualitative Inquiry* **9**, (3), 335-354.
- Costain Schou K. & Hewison J. (1999) *Experiencing cancer: Quality of life in treatment*. Open University Press: Buckingham.
- Creswell J. (2007) *Qualitative Inquiry & Research Design: Choosing Among Five Approaches*. Sage: California.
- Crouch M. & McKenzie H. (2000) Social realities of loss and suffering following mastectomy. *Health* **4**, (2), 196-215.
- Crouch M. & McKenzie H. (2006) The logic of small samples in interview-based qualitative research. *Social Science Information* **45**, (4), 483-499.
- Crowley-Matoka M. (2005) Desperately seeking "normal": the promise and perils of living with kidney transplantation. *Social Science & Medicine* **61**, (4), 821-831.
- Davies N. (2009) Cancer survivorship: living with or beyond cancer. *Cancer Nursing Practice* **8**, (7), 29-35.
- Davies N., Batehup L. & Thomas R. (2011) The role of diet and physical activity in breast, colorectal, and prostate cancer survivorship: a review of the literature. *British Journal of Cancer* **105**, S52-S73.
- Deimling G. T., Bowman K. F., Sterns S., Wagner L. J. & Kahana B. (2006a) Cancer-related health worries and psychological distress among older adult, long-term cancer survivors. *Psycho Oncology* **15**, (4), 306-320.
- Deimling G. T., Bowman K. F. & Wagner L. J. (2007) Cancer survivorship and identity among long-term survivors. *Cancer Investigation* **25**, (8), 758-765.
- Deimling G. T., Wagner L. J., Bowman K. F., Sterns S., Kercher K. & Kahana B. (2006b) Coping among older-adult, long-term cancer survivors. *Psycho Oncology* **15**, (2), 143-159.
- Department-of-Health (2007) Cancer Reform Strategy.
- Department-of-Health (2010) National Cancer Survivorship Initiative Vision.
- Department-of-Health (2012) Quality of Life of Cancer Survivors in England: Report on a pilot survey using Patient Reported Outcome Measures (PROMS).
- Die-Trill M. (2000) Beliefs about cancer causation and their influence on family function. In: *Cancer and the Family*. Baider, L., Cooper, C. L. & Kaplan De-Nour, A. (Eds.), John Wiley & Sons: New York, p. 119-133. 2nd ed
- Dirksen S. K. (1995) Search for meaning in long-term cancer survivors. (Research). *Journal of Advanced Nursing* (pp), Apr 1995.
- Douglas M. (1984 (1966)) *Purity and Danger: An analysis of the concepts of pollution and taboo*. Routledge: Abingdon.
- Dow K. (1990) The Enduring Seasons in Survival. *Oncology Nursing Forum* **17**, (4), 511-516.
- Dow K. H., Ferrell B. R., Haberman M. R. & Eaton L. (1999) The meaning of quality of life in cancer survivorship. *Oncology Nursing Forum* **26**, (3), 519-528.

- Doyle N. (2008) Cancer survivorship: evolutionary concept analysis. *Journal of Advanced Nursing* **62**, (4), 499-509.
- Drew S. (2003) Self-reconstruction and biographical revisioning: survival following cancer in childhood or adolescence. *Health* **7**, (2), 181-199.
- Dyregov K. (2004) Bereaved parents' experience of research participation. *Social Science & Medicine* **58**, 391-400.
- Elliott J. (2005) *Using Narrative in Social Research: Qualitative and Quantitative Approaches*. Sage: London.
- Ferrell B., Grant M., Funk B. & Otis-Green S. (1997) Quality of life in breast cancer survivors as identified by focus groups. *Psycho Oncology* **6**, (1), 13-23.
- Ferrell B. R., Dow K. H., Leigh S., Ly J. & Gulasekaram P. (1995) Quality of life in long-term cancer survivors. *Oncology Nursing Forum* **22**, (6), 915-922.
- Feuerstein M. (2007a) Cancer survivorship: Research, practice, and policy. In: *Handbook of cancer survivorship*. Feuerstein, M. (ed.) Springer: New York, p. 483-494.
- Feuerstein M. (2007b) Defining cancer survivorship. *Journal of Cancer Survivorship* **1**, 5-7.
- Fleer J., Hoekstra H. J., Sleijfer D. T., Tuinman M. A. & Hoekstra-Weebers J. E. (2006) The role of meaning in the prediction of psychosocial well-being of testicular cancer survivors. *Quality of Life Research* **15**, (4), 705-717.
- Foley K., Farmer D., Petronis V., Smith R., McGraw S., Smith K., Carver C. & Avis N. (2006) A qualitative exploration of the cancer experience among long-term survivors: comparisons by cancer type, ethnicity, gender, and age. *Psycho Oncology* **15**, 248-258.
- Forbat L. & Henderson J. (2003) "Stuck in the middle with you": The ethics and process of qualitative research with two people in an intimate relationship. *Qualitative Health Research* **13**, (10), 1453-1462.
- Forss A., Tishelman C., Widmark C. & Sachs L. (2004) Women's experiences of cervical cellular changes: an unintentional transition from health to liminality? *Sociology of Health & Illness* **26**, (3), 306-325.
- Fossa S. D. & Dahl A. A. (2008) Fertility and sexuality in young cancer survivors who have adult-onset malignancies. *Hematology Oncology Clinics of North America* **22**, (2), 291-303.
- Foster C., Wright D., Hill H., Hopkinson J. & Roffe L. (2009) Psychosocial implications of living 5 years or more following a cancer diagnosis: a systematic review of the research evidence. *European Journal of Cancer Care* **18**, (3), 223-247.
- Frank A. (1995) *The Wounded Storyteller: Body, Illness and Ethics*. The University of Chicago Press: Chicago.
- Frank A. (2000) The Standpoint of Storyteller. *Qualitative Health Research* **10**, (3), 354-365.
- Frank A. (2010) In defence of narrative exceptionalism. *Sociology of Health & Illness* **32**, (4), 665-667.
- Frankl V. (2004) *Man's search for meaning: the classic tribute to hope from the Holocaust*. Rider: London.

- Froggatt K. (1997) Rites of passage and the hospice culture. *Mortality* **2**, (2), 123-136.
- Giddens A. (2009) *Sociology*. Polity Press: Cambridge.
- Gil K. M., Mishel M. H., Belyea M., Germino B., Porter L. S., LaNey I. C. & Stewart J. (2004) Triggers of uncertainty about recurrence and long-term treatment side effects in older African American and Caucasian breast cancer survivors. *Oncology Nursing Forum* **31**, (3), 633-639.
- Gotay C. & Muraoka M. (1998) Quality of life in long-term survivors of adult-onset cancers. *Journal of the National Cancer Institute* **90**, (9), 656-667.
- Grainger R. (1974) *The language of the rite*. Darton, Longman and Todd: London.
- Gray R. E., Wassersug R. J., Sinding C., Barbara A. M., Trosztmer C. & Fleshner N. (2005) The experiences of men receiving androgen deprivation treatment for prostate cancer: a qualitative study. *Canadian Journal of Urology* **12**, (4), 2755-2763.
- Greenwald H. P. & McCorkle R. (2007) Remedies and life changes among invasive cervical cancer survivors. *Urologic Nursing* **27**, (1), 47-53.
- Griffiths J., Willard C., Burgess A., Amir Z. & Luker K. (2007) Meeting the ongoing needs of survivors of rarer cancer. *European Journal of Oncology Nursing* **11**, (5), 434-441.
- Grinyer A. (2004) The narrative correspondence method: what a follow-up study can tell us about the longer term effect on participants in emotionally demanding research. *Qualitative Health Research* **14**, (10), 1326-1341.
- Gunaratnam Y. (2009) Narrative interviews and research. In: *Narrative and stories in health care : illness, dying and bereavement*. Gunaratnam, Y. & Oliviere, D. (Eds.), Oxford University Press: Oxford, p. 47-61.
- Hall J. (2011) Narrative methods in a study of trauma recovery. *Qualitative Health Research* **21**, (1), 3-13.
- Hammersley M. (1992) *What's wrong with ethnography?* Routledge: Abingdon.
- Hammersley M. (2002) Ethnography and realism. In: *The Qualitative Researcher's Companion*. Huberman, A. & Miles, M. (Eds.), Sage: Thousand Oaks, p. 65-80.
- Hara R. & Blum D. (2009) Social well-being and cancer survivorship. *Oncology* **23**, (2 Suppl Nurse Ed), 40-50.
- Harrington C. B., Hansen J. A., Moskowitz M., Todd B. L. & Feuerstein M. (2010) It's not over when it's over: Long-term symptoms in cancer survivors: A systematic review. *International Journal of Psychiatry in Medicine* **40**, (2), 163-181.
- Harrison S. E., Watson E. K., Ward A. M., Khan N. F., Turner D., Adams E., Forman D., Roche M. F. & Rose P. W. (2011) Primary health and supportive care needs of long-term cancer survivors: a questionnaire survey. *Journal of Clinical Oncology* **29**, (15), 2091-2098.
- Harrison T. C. & Kahn D. L. (2004) Disability rites: the cultural shift following impairment. *Family & Community Health* **27**, (1), 86-93.

- Harrop J., Dean J. & Paskett E. (2011) Cancer survivorship research: a review of the literature and summary of current NCI-designated cancer center projects. *Cancer Epidemiology Biomarkers & Prevention* **20**, (10), 2042-2047.
- Harrow A., Wells M., Barbour R. S. & Cable S. (2008) Ambiguity and uncertainty: The ongoing concerns of male partners of women treated for breast cancer. *European Journal of Oncology Nursing* **12**, (4), 349-356.
- Helgeson V. S. (2010) Corroboration of growth following breast cancer: ten years later. *Journal of Social and Clinical Psychology* **29**, (5), 546-574.
- Helgeson V. S. (2011) Survivor centrality among breast cancer survivors: implications for well-being. *Psycho Oncology* **20**, 517-524.
- Helman C. (2007) *Culture, health and illness*. Hodder Arnold: London.
- Henoch I. & Danielson E. (2009) Existential concerns among patients with cancer and interventions to meet them: an integrative literature review. *Psycho Oncology* **18**, 225-236.
- Hewitt M., Greenfield S. & Stovall E. (2005) *From Cancer Patient to Cancer Survivor: Lost in Transition*. Institute of Medicine.
- Hockey J. (2002) The importance of being intuitive: Arnold Van Gennep's The Rites of Passage. *Mortality* **7**, (2), 210-217.
- Hockey J. & James A. (1993) *Growing up and growing old: ageing and dependency in the life course*. Sage: London.
- Hodgkinson K., Butow P., Fuchs A., Hunt G. E., Stenlake A., Hobbs K. M., Brand A. & Wain G. (2007) Long-term survival from gynecologic cancer: Psychosocial outcomes, supportive care needs and positive outcomes. *Gynecologic Oncology* **104**, (2), 381-389.
- Hoffman B. & Stovall E. (2006) Survivorship perspectives and advocacy. *Journal of Clinical Oncology* **24**, (32), 5154-5159.
- Holland J. C. (2002) History of psycho-oncology: Overcoming attitudinal and conceptual barriers. *Psychosomatic Medicine* **64**, (2), 206-221.
- Holstein J. & Gubrium J. (1995) *The Active Interview*. Sage: Thousand Oaks.
- Holstein J. & Gubrium J. (2004) The active interview. In: *Qualitative research: Theory, method and practice*. Silverman, D. (ed.) Sage: London, p. 140-161.
- Horlick-Jones T. (2011) Understanding fear of cancer recurrence in terms of damage to 'everyday health competence'. *Sociology of Health & Illness* **33**, (6), 884-898.
- Hubbard G. & Forbat L. (2012) Cancer as biographical disruption: constructions of living with cancer. *Supportive Care in Cancer* **20**, (9), 2033-2040.
- Hubbard G., Kidd L. & Kearney N. (2010) Disrupted lives and threats to identity: the experiences of people with colorectal cancer within the first year following diagnosis. *Health* **14**, (2), 131-146.
- Hughes N., Jose Closs S. & Clark D. (2009) Experiencing cancer in old age: a qualitative systematic review. *Qualitative Health Research* **19**, (8), 1139-1153.
- Hyden L.-C. (1997) Illness and narrative. *Sociology of Health & Illness* **19**, (1), 48-69.
- Jackson J. E. (2005) Stigma, liminality, and chronic pain: Mind-body borderlands. *American Ethnologist* **32**, (3), 332-353.

- Jacobsen P. B. & Jim H. S. (2011) Consideration of quality of life in cancer survivorship research. *Cancer Epidemiology Biomarkers & Prevention* **20**, (10), 2035-2041.
- Jansen L., Hoffmeister M., Chang-Claude J., Brenner H. & Arndt V. (2011) Benefit finding and post-traumatic growth in long-term colorectal cancer survivors: prevalence, determinants, and associations with quality of life. *British Journal of Cancer* **105**, (8), 1158-1165.
- Jefford M., Karahalios E., Pollard A., Baravelli C., Carey M., Franklin J., Aranda S. & Schofield P. (2008) Survivorship issues following treatment completion - results from focus groups with Australian cancer survivors and health professionals. *Journal of Cancer Survivorship* **2**, 20-32.
- Johnson B. & Macleod Clarke J. (2003) Collecting sensitive data: the impact on researchers. *Qualitative Health Research* **13**, (3), 421-434.
- Kahana B., Kahana E., Deimling G., Sterns S. & Vangunten M. (2011) Determinants of altered life perspectives among older-adult long-term cancer survivors. *Cancer Nursing* **34**, (3), 209-218.
- Kaiser K. (2008) The meaning of the survivor identity for women with breast cancer. *Social Science & Medicine* **67**, (1), 79-87.
- Kaiser K. (2009) Protecting respondent confidentiality in qualitative research. *Qualitative Health Research* **19**, (11), 1632-1641.
- Kaplan M. (2008) Cancer survivorship: meeting psychosocial needs. *Clinical Journal of Oncology Nursing* **12**, (6), 989-992.
- Kaufman S. (2000) In the shadow of "Death with Dignity": Medicine and cultural quandaries of the vegetative state. *American Anthropologist* **102**, (1), 69-83.
- Kelly K., Shah N., Shedlosky-Shoemaker R., Porter K. & Agnese D. (2011) Living post-treatment: definitions of those with history and no history of cancer. *Journal of Cancer Survivorship* **5**, 158-166.
- Khan N. F., Harrison S., Rose P. W., Ward A. & Evans J. (2012) Interpretation and acceptance of the term 'cancer survivor': a United Kingdom-based qualitative study. *European Journal of Cancer Care* **21**, 177-186.
- Kleinman A. (1988) *The Illness Narratives: Suffering, Healing and the Human Condition*. Basic Books: USA.
- Koocher G. & O'Malley J. (1981) *The Damocles Syndrome: Psychosocial consequences of surviving childhood cancer*. McGraw-Hill: New York.
- Lance-Armstrong-Foundation (2004) A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies.
- Langellier K. M. (2001) "You're marked": Breast cancer, tattoo, and the narrative performance of identity. In: *Narrative and Identity: Studies in Autobiography, Self and Culture* Brockmeier, J. & Carbaugh, D. (Eds.), John Benjamins Publishing Company: Philadelphia, p. 145-184.
- Lawton J. (2003) Lay experiences of health and illness: past research and future agendas. *Sociology of Health & Illness* **25**, 23-40.
- Lazarus R. & Folkman S. (1984) *Stress, appraisal and coping*. Springer: New York.
- Leigh S. (1994) Cancer survivorship: a consumer movement. *Seminars in Oncology* **21**, (6), 783-786.

- Leigh S. (2007) Cancer survivorship: a nursing perspective. In: *Cancer survivorship: Today and tomorrow*. Ganz, P. A. (ed.) Springer: New York, p. 8-13.
- Leigh S. (2008) The changing legacy of cancer: issues of long-term survivorship. *Nursing Clinics North America* **43**, (2), 243-258.
- Leigh S. & Logan C. (1991) The cancer survivorship movement. *Cancer Investigation* **9**, (5), 571-579.
- Lelorain S., Bonnaud-Antignac A. & Florin A. (2010) Long Term Posttraumatic Growth After Breast Cancer: Prevalence, Predictors and Relationships with Psychological Health. *Journal of Clinical Psychology in Medical Settings* **17**, (1), 14-22.
- Lewis J. (2003) Design Issues. In: *Qualitative research practice: a guide for social science students and researchers*. Ritchie, J. & Lewis, J. (Eds.), Sage: London, p. 47-76.
- Lewis M. (2007) *Medicine and Care of the Dying*. Oxford University Press: Oxford.
- Lieblich A., Tuval-Mashiach R. & Zilber T. (1998) *Narrative research: reading, analysis and interpretation*. Sage: Thousand Oaks.
- Lincoln Y. & Guba E. (1985) *Naturalistic Inquiry*. Sage: Newbury Park.
- Linde C. (1993) *Life stories: the creation of coherence*. Oxford University Press: Oxford.
- Lipowski Z. (1970) Physical illness, the individual, and the coping process. *Psychiatric Medicine* **1**, 91-102.
- Little M. (2004) Chronic illness and the experience of surviving cancer. *Internal Medicine Journal* **34**, (4), 201-202.
- Little M., Jordens C., Paul K., Montgomery K. & Philipson B. (1998) Liminality: A major category of the experience of cancer illness. *Social Science & Medicine* **47**, (10), 1485-1494.
- Little M., Paul K., Jordens C. & Sayers E.-J. (2002) Survivorship and discourses of identity. *Psycho Oncology* **11**, (2), 170-178.
- Little M. & Sayers E.-J. (2004a) The skull beneath the skin: cancer survival and awareness of death. *Psycho Oncology* **13**, (3), 190-198.
- Little M. & Sayers E.-J. (2004b) While there's life... hope and the experience of cancer. *Social Science & Medicine* **59**, (6), 1329-1337.
- Loescher L. J., Clark L., Atwood J. R., Leigh S. & Lamb G. (1990) The impact of the cancer experience on long-term survivors. *Oncology Nursing Forum* **17**, (2), 223-229.
- Lucas P., Baird J., Arai L., Law C. & Roberts H. (2007) Worked examples of alternative methods for the synthesis of qualitative and quantitative research in systematic reviews. *BMC Medical Research Methodology* **7**, (4).
- Luxford Y. (2003) Troublesome breasts: older women living in the liminal state of being 'at risk' of breast cancer. *Health Sociology Review* **12**, (2), 146-154.
- MacFarlane A. & O'Reilly-de Brun M. (2012) Using a theory-driven conceptual framework in qualitative health research. *Qualitative Health Research* **22**, (5), 607-618.
- Macmillan-Cancer-Support (2013) Cured-but at what cost? Long-term consequences of cancer and its treatment.

- Maddams J., Brewster D., Gavin A., Steward J., Elliott J., Utley M. & Moller H. (2009) Cancer prevalence in the United Kingdom: estimates for 2008. *British Journal of Cancer* **101**, (3), 541-547.
- Mah K., Bezjak A., Loblaw D., Gotowiec A. & Devins G. (2011) Do ongoing lifestyle disruptions differ across cancer types after the conclusion of cancer treatment? *Journal of Cancer Survivorship* **5**, 18-28.
- Martin-McDonald K. & Biernoff D. (2002) Initiation into a dialysis-dependent life: an examination of rites of passage. *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association* **29**, (4), 347-352.
- Mason J. (2002) *Qualitative Researching*. Sage: London.
- Mathers N., Watt G. & Perrin N. (2009) Towards consensus for best practice: Use of patient records from general practice for research. Wellcome Trust.
- Mathieson C. & Stam H. (1995) Renegotiating identity: cancer narratives. *Sociology of Health & Illness* **17**, (3), 283-306.
- Mays N. & Pope C. (2000) Assessing quality in qualitative research. *BMJ* **320**, 50-52.
- McGrath P. (2004a) Positive outcomes for survivors of haematological malignancies from a spiritual perspective. *International Journal of Nursing Practice* **10**, 280-291.
- McGrath P. (2004b) Reflections on serious illness as spiritual journey by survivors of haematological malignancies. *European Journal of Cancer Care* **13**, 227-237.
- McKenzie H. (2004) Personal and collective fears of death: A complex intersection for cancer survivors. In: *Making sense of death and dying*. Fagan, A. (ed.) Rodopi: Amsterdam, p. 107-124.
- McKenzie H. & Crouch M. (2004) Discordant feelings in the Lifeworld of Cancer Survivors. *Health* **8**, (2), 139-157.
- Mead G. (1934) *Mind, Self, and Society*. University of Chicago Press: Chicago.
- Meneses K. D., McNees P., Loerzel V. W., Su X., Zhang Y. & Hassey L. A. (2007) Transition from treatment to survivorship: effects of a psychoeducational intervention on quality of life in breast cancer survivors. *Oncology Nursing Forum* **34**, (5), 1007-1016.
- Miller K., Merry B. & Miller J. (2008) Seasons of survivorship revisited. *Cancer Journal* **14**, (6), 369-374.
- Miller L. (2012) Sources of uncertainty in cancer survivorship. *Journal of Cancer Survivorship* **6**, 431-440.
- Mishel M. H. (1990) Reconceptualization of the uncertainty in illness theory. *Journal of Nursing Scholarship* **22**, (4), 256-261.
- Mishel M. H., Germino B., Gil K. M., Belyea M., LaNey I. C., Stewart J., Porter L. & Clayton M. F. (2005) Benefits from an uncertainty management intervention for African-American and Caucasian older long-term breast cancer survivors. *Psycho Oncology* **14**, 962-978.
- Mishler E. (1986) *Research interviewing: context and narrative*. Harvard University Press: Cambridge Massachusetts.
- Mols F., Korfage I. J., Vingerhoets A. J., Kil P. J., Coebergh J. W., Essink-Bot M. L. & van de Poll-Franse L. V. (2009a) Bowel, urinary, and sexual problems among

- long-term prostate cancer survivors: a population-based study. *International Journal of Radiation Oncology, Biology, Physics* **73**, (1), 30-38.
- Mols F., Vingerhoets A. J., Coebergh J. W. & van de Poll-Franse L. V. (2009b) Well-being, posttraumatic growth and benefit finding in long-term breast cancer survivors. *Psychology & Health* **24**, (5), 583-595.
- Molzahn A. E., Bruce A. & Sheilds L. (2008) Learning from stories of people with chronic kidney disease. *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association* **35**, (1), 13-20.
- Morgan M. A. (2009) Cancer Survivorship: History, Quality-of-Life Issues, and the Evolving Multidisciplinary Approach to Implementation of Cancer Survivorship Care Plans. *Oncology Nursing Forum* **36**, (4), 429-436.
- Morris B. A., Campbell M., Dwyer M., Dunn J. & Chambers S. K. (2011) Survivor identity and post-traumatic growth after participating in challenge-based peer-support programmes. *British Journal of Health Psychology* **16**, (3), 660-674.
- Morris S. (2001) Joint and individual interviewing in the context of cancer. *Qualitative Health Research* **11**, (4), 553-567.
- Mullan F. (1985) Seasons of survival: reflections of a physician with cancer. *New England Journal of Medicine* **313**, (4), 270-273.
- Murphy R., Scheer J., Murphy Y. & Mack R. (1988) Physical disability and social liminality: A study in the rituals of adversity. *Social Science & Medicine* **26**, (2), 235-242.
- Mwaria C. B. (1990) The concept of self in the context of crisis: a study of families of the severely brain-injured. *Social Science & Medicine* **30**, (8), 889-893.
- Naaman S., Radwan K. & Johnson S. (2009) Coping with early breast cancer: Couple adjustment processes and couple-based intervention. *Psychiatry: Interpersonal and Biological Processes* **72**, (4), 321-345.
- Naus M. J., Ishler M. D., Parrott C. E. & Kovacs S. A. (2009) Cancer Survivor Adaptation Model: Conceptualizing Cancer as a Chronic Illness. *Journal of Clinical Psychology* **65**, (12), 1350-1359.
- Navon L. & Morag A. (2004) Liminality as biographical disruption: unclassifiability following hormonal therapy for advanced prostate cancer. *Social Science & Medicine* **58**, (11), 2337-2347.
- O'Mahoney J. M. & Carroll R. A. (1997) The impact of breast cancer and its treatment on marital functioning. *Journal of Clinical Psychology in Medical Settings* **4**, (4), 397-415.
- Office-for-National-Statistics (2011) Cancer survival in England. Patients diagnosed 2004–2008, followed up to 2009. *Statistical Bulletin*. Office for National Statistics.
- Ollerenshaw J. & Creswell J. (2002) Narrative Research: A comparison of two restorying data analysis approaches. *Qualitative Inquiry* **8**, (3), 329-347.
- Park C. & Folkman S. (1997) Meaning in the context of stress and coping. *Review of General Psychology* **1**, (2), 115-144.

- Park C., Zlateva I. & Blank T. (2009) Self identity after cancer: "survivor", "victim", "patient" and "person with cancer". *Journal of General Internal Medicine* **24**, (Suppl 2), 430-435.
- Paterson B., Gregory D. & Thorne S. (1999) A protocol for researcher safety. *Qualitative Health Research* **9**, (2), 259-269.
- Peck S. (2008) Survivorship: a concept analysis. *Nursing Forum* Apr/Jun.
- Pedro L. (2001) Quality of life for long-term survivors of cancer: influencing variables. *Cancer Nursing* **24**, (1), 1-11.
- Peel E., Parry O., Douglas M. & Lawton J. (2006) "It's no skin off my nose": why people take part in qualitative research. *Qualitative Health Research* **16**, (10), 1335-1349.
- Pelusi J. (1997) The lived experience of surviving breast cancer. *Oncology Nursing Forum* **24**, (8), 1343-1353.
- Persson L. & Hallberg I. R. (2004) Lived experience of survivors of leukemia or malignant lymphoma. *Cancer Nursing* **27**, (4), 303-313.
- Phillips J. L. & Currow D. C. (2010) Cancer as a chronic disease. *Collegian: Journal of the Royal College of Nursing, Australia* **17**, (2), 47-50.
- Phoenix A. (2008) Analysing narrative contexts. In: *Doing Narrative Research*. Andrews, M., Squire, C. & Tamboukou, M. (Eds.), Sage: London, p. 64-77.
- Radley A. (1994) *Making sense of illness: the social psychology of health and disease*. Sage: London.
- Ramirez M., McMullen C., Grant M., Altschuler A., Hornbrook M. C. & Krouse R. S. (2009) Figuring out sex in a reconfigured body: experiences of female colorectal cancer survivors with ostomies. *Women & Health* **49**, (8), 608-624.
- Rasmussen D. & Elverdam B. (2007) Cancer survivors' experience of time - time disruption and time appropriation. *Journal of Advanced Nursing* **57**, (6), 614-622.
- Richards H. & Schwartz L. (2002) Ethics of qualitative research: are there special issues for health services research. *Family Practice* **19**, 135-139.
- Richards M., Corner J. & Maher J. (2011) The National Cancer Survivorship Initiative: new and emerging evidence on the ongoing needs of cancer survivors. *British Journal of Cancer* **105**, S1-S4.
- Richardson A., Addington-Hall J., Amir Z., Foster C., Stark D., Armes J., Brearley S. G., Hodges L., Hook J., Jarrett N., Stamatakis Z., Scott I., Walker J., Ziegler L. & Sharpe M. (2011) Knowledge, ignorance and priorities for research in key areas of cancer survivorship: findings from a scoping review. *British Journal of Cancer* **105**, S82-S94.
- Richardson A., Addington-Hall J., Stark D., Foster C., Amir Z. & Sharpe M. (2009) Determining Research Priorities for Cancer Survivorship: Consultation and Evidence Review. Compass Collaborative and Cancer Experience Collaborative.
- Riessman C. (1993) *Narrative Analysis*. Sage: London.
- Riessman C. (2008) *Narrative Methods in the Human Sciences*. Sage: Thousand Oaks.

- Ritchie J., Lewis J. & Elam G. (2003a) Designing and selecting samples. In: *Qualitative Research Practice: A guide for social science students and researchers*. Ritchie, J. & Lewis, J. (Eds.), Sage: London, p. 77-108.
- Ritchie J., Spencer L. & O'Connor W. (2003b) Carrying out qualitative analysis. In: *Qualitative Research Practice: A guide for social science students and researchers*. Ritchie, J. & Lewis, J. (Eds.), Sage: London, p. 219-262.
- Rozmovits L. & Ziebland S. (2004) Expressions of loss of adulthood in the narratives of people with colorectal cancer. *Qualitative Health Research* **14**, (2), 187-203.
- Sanders S., Pedro L. W., Bantum E. O. & Galbraith M. E. (2006) Couples surviving prostate cancer: Long-term intimacy needs and concerns following treatment. *Clinical Journal of Oncology Nursing* **10**, (4), 503-508.
- Sarre G., Dyas J., Clarke A. & Keen C. (2008) PROSPeR: An analytical framework for planning and sustaining recruitment to research studies in primary care based on evidence from the literature. Trent RDSU and National Institute for Health Research.
- Schroevens M., Kraaij V. & Garnefski N. (2011) Cancer patients' experience of positive and negative changes due to the illness: relationships with psychological well-being, coping, and goal reengagement. *Psycho Oncology* **20**, 165-172.
- Schroevens M., Ranchor A. V. & Sanderman R. (2006) Adjustment to cancer in the 8 years following diagnosis: a longitudinal study comparing cancer survivors with healthy individuals. *Social Science & Medicine* **63**, (3), 598-610.
- Scott S., Prior L., Wood F. & Gray J. (2005) Repositioning the patient: The implications of being 'at risk'. *Social Science & Medicine* **60**, (8), 1869-1879.
- Seale C. (1999) Quality in Qualitative Research. *Qualitative Inquiry* **5**, (4), 465-478.
- Sekse R. J. T., Raaheim M., Blaaka G. & Gjengedal E. (2009) Cancer as a life-changing process: Women's experiences five years after treatment for gynaecological cancer. *International Journal of Qualitative Studies on Health and Well-Being* **4**, (4), 288-298.
- Sekse R. J. T., Raaheim M., Blaaka G. & Gjengedal E. (2010) Life beyond cancer: women's experiences 5 years after treatment for gynaecological cancer. *Scandinavian Journal of Caring Sciences*.
- Shapiro S., Angus L. & Davis C. (1997) Identity and Meaning in the Experience of Cancer: Three Narrative Themes. *Journal of Health Psychology* **2**, (4), 539-554.
- Shomaker D. J. (1989) Age disorientation, liminality and reality: The case of the Alzheimer's patient. *Medical Anthropology* **12**, (1), 91-101.
- Silverman D. (2010) *Doing Qualitative Research*. Sage: London.
- Sinding C. & Gray R. (2004) Active aging-spunky survivorship? Discourses and experiences of the years beyond breast cancer. *Journal of Aging Studies* **19**, 147-161.
- Skaali T., Fossa S. D., Bremnes R., Dahl O., Haaland C. F., Hauge E. R., Klepp O., Oldenburg J., Wist E. & Dahl A. A. (2009) Fear of recurrence in long-term testicular cancer survivors. *Psycho Oncology* **18**, (6), 580-588.

- Skultans V. (1998) Anthropology and narrative. In: *Narrative Based Medicine: Dialogue and discourse in clinical practice*. Greenhalgh, T. & Hurwitz, B. (Eds.), BMJ Books: London, p. 225-233.
- Smith B. (2007) The state of the art in narrative inquiry. *Narrative Inquiry* **17**, (2), 391-398.
- Smith B. & Sparkes A. (2008) Narrative and its potential contribution to disability studies. *Disability & Society* **23**, (1), 17-28.
- Smith D. (1979) Survivors of Serious Illness. *American Journal of Nursing* **79**, 441-446.
- Somers M. (1994) The Narrative Constitution of Identity: A Relational and Network Approach. *Theory and Society* **23**, (5), 605-649.
- Spencer L., Ritchie J., Lewis J. & Dillon L. (2003) Quality in Qualitative Evaluation: A framework for assessing research evidence. National Centre for Social Research.
- Squier S. (2004) *Liminal lives: imagining the human at the frontiers of biomedicine*. Duke University Press: Durham & London.
- Stake R. (1995) *The Art of Case Study Research*. Sage: Thousand Oaks.
- Stake R. (2005) Qualitative Case Studies. In: *The Sage Handbook of Qualitative Research*. Denzin, N. & Lincoln, Y. (Eds.), Sage: London, p. 443-466.
- Stake R. (2006) *Multiple Case Study Analysis*. The Guildford Press: New York.
- Stephens M. (2004) Understanding the long-term challenges of cancer survivorship. *Nursing Times* **100**, (30), 30-31.
- Stewart D. E., Cheung A. M., Duff S., Wong F., McQuestion M., Cheng T., Purdy L. & Bunston T. (2001) Attributions of cause and recurrence in long-term breast cancer survivors. *Psycho Oncology* **10**, (2), 179-183.
- Sugimura H. & Yang P. (2006) Long-term survivorship in lung cancer: a review. [Review] [85 refs]. *Chest* **129**, (4), 1088-1097.
- Taylor B. & de Vocht H. (2011) Interviewing separately or as couples? Considerations of authenticity of method. *Qualitative Health Research* **21**, (11), 1576-1587.
- Taylor C., Richardson A. & Cowley S. (2010) Restoring embodied control following surgical treatment for colorectal cancer: A longitudinal qualitative study. *International Journal of Nursing Studies* **47**, (8), 946-956.
- Taylor E. (1995) Whys and wherefores: adult patient perspectives of the meaning of cancer. *Seminars in Oncology Nursing* **11**, (1), 32-40.
- Taylor S. (1983) Adjustment to threatening events: a theory of cognitive adaptation. *American Psychologist* **November**, 1161-1173.
- Tedeschi R. & Calhoun L. (1995) *Trauma & Transformation: Growing in the aftermath of suffering*. Thousand Oaks: Sage.
- Tedeschi R., Park C. & Calhoun L. (1998) Posttraumatic growth: conceptual issues. In: *Posttraumatic growth: positive changes in the aftermath of crisis*. Tedeschi, R., Park, C. & Calhoun, L. (Eds.), Lawrence Erlbaum Associates: New Jersey, p. 1-22.
- Thaler-DeMers D. (2001) Intimacy issues: sexuality, fertility, and relationships. *Seminars in Oncology Nursing* **17**, (4), 255-262.

- Thomas C. (2010) Negotiating the contested terrain of narrative methods in illness contexts. *Sociology of Health & Illness* **32**, (4), 647-660.
- Thomas-Maclean R. (2005) Beyond dichotomies of health and illness: life after breast cancer. *Nursing Inquiry* **12**, (3), 200-209.
- Thompson K. (2007) Liminality as a descriptor for the cancer experience. *Illness, Crisis, & Loss* **15**, (4), 333-351.
- Thornton A. & Perez M. (2007) Interpersonal relationships. In: *Handbook of Cancer Survivorship*. Feuerstein, M. (ed.) Springer: New York, p. 191-210.
- Thornton A. A. (2002) Perceiving benefits in the cancer experience. *Journal of Clinical Psychology in Medical Settings* **9**, (2), 153-165.
- Tod A., Warnock C. & Allmark P. (2011) A critique of positive thinking for patients with cancer. *Nursing Standard* **25**, (39), 43-47.
- Tomich P., Helgeson V. & Vache E. (2005) Perceived growth and decline following breast cancer: a comparison to age-matched controls 5-years later. *Psycho Oncology* **14**, 1018-1029.
- Tomich P. L. & Helgeson V. S. (2002) Five years later: a cross-sectional comparison of breast cancer survivors with healthy women. *Psycho Oncology* **11**, (2), 154-169.
- Treloar C. & Rhodes T. (2009) The Lived Experience of Hepatitis C and its treatment among injecting drug users: qualitative synthesis. *Qualitative Health Research* **19**, (9), 1321-1334.
- Tritter J. & Calnan M. (2002) Cancer as a chronic illness? Reconsidering categorization and exploring experience. *European Journal of Cancer Care* **11**, 161-165.
- Tuinman M. A., Fleer J., Sleijfer D. T., Hoekstra H. J. & Hoekstra-Weebers J. E. (2005) Marital and sexual satisfaction in testicular cancer survivors and their spouses. *Supportive Care in Cancer* **13**, (7), 540-548.
- Turner V. (1967) *The Forest of Symbols: Aspects of Ndembu Ritual*. Cornell University Press: New York.
- Turner V. (1969) *The Ritual Process: Structure and anti-structure*. Routledge: London.
- Twombly R. (2004) What's in a name: who is a cancer survivor? *Journal of the National Cancer Institute* **96**, (19), 1414-1415.
- Underwood M., Satterthwait L. & Bartlett H. (2010) Reflexivity and minimization of the impact of age-cohort differences between researcher and research participants. *Qualitative Health Research* **20**, (11), 1585-1595.
- Utley R. (1999) The evolving meaning of cancer for long-term survivors of breast cancer. *Oncology Nursing Forum* **26**, (9), 1519-1523.
- Vachon M. (2001) The meaning of illness to a long-term survivor. *Seminars in Oncology Nursing* **17**, (4), 279-283.
- Van Gennep A. (1960) *The Rites of Passage*. University of Chicago Press: Chicago.
- Van Maanen J. (1988) *Tales of the field: on writing ethnography*. University of Chicago Press: Chicago.
- Vivar C. G. & McQueen A. (2005) Informational and emotional needs of long-term survivors of breast cancer. *Journal of Advanced Nursing* **51**, (5), 520-528.

- Walker L. & Robinson J. (2012) Sexual adjustment to androgen deprivation therapy: struggles and strategies. *Qualitative Health Research* **22**, (4), 452-465.
- Walls P., Parahoo K., Fleming P. & McCaughan E. (2010) Issues and considerations when researching sensitive issues with men: examples from a study of men and sexual health. *Nurse Researcher* **18**, (1), 26-34.
- Wallwork L. & Richardson A. (1994) Beyond cancer: changes, problems and needs expressed by adult lymphoma survivors attending an out-patients clinic. *European Journal of Cancer Care* **3**, (3), 122-132.
- Walt G. (1994) How far does research influence policy? *European Journal of Public Health* **4**, 233-235.
- Ward E., Bower P., Collier D., Delaney B., Graffy J., Kinmonth A.-L., Miller J. & Wallace P. (2010) Primary Care Research Recruitment: A Practical Guide. PCRN and National Institute for Health Research.
- Watson E. K., Rose P. W., Loftus R. & Devane C. (2011) Cancer survivorship: the impact on primary care. *British Journal of General Practice* **61**, (592), 763-765.
- Weihls K. & Reiss D. (2000) Family reorganization in response to cancer: a developmental perspective. In: *Cancer and the Family*. Baider, L., Cooper, C. L. & Kaplan De-Nour, A. (Eds.), John Wiley & Sons: New York, p. 17-39. 2nd ed
- Wengraf T. (2001) *Qualitative Research Interviewing: Biographic Narrative and Semi-Structured Methods*. Sage: London.
- Williams G. (1984) The genesis of chronic illness: narrative reconstruction. *Sociology of Health & Illness* **6**, (2), 175-200.
- Wilson E., Elkan R. & Cox K. (2007) Closure for patients at the end of a cancer clinical trial: literature review. *Journal of Advanced Nursing* **59**, (5), 445-453.
- Wittmann D., Northouse L., Foley S., Gilbert S., Wood D. P., Jr., Balon R. & Montie J. E. (2009) The psychosocial aspects of sexual recovery after prostate cancer treatment. *International Journal of Impotence Research* **21**, (2), 99-106.
- Yin R. (2003) *Case Study Research: Design and Methods*. Sage: Thousand Oaks.
- Zebrack B. (2000a) Cancer Survivor Identity and Quality of Life. *Cancer Practice* **8**, (5), 238-242.
- Zebrack B. (2000b) Cancer survivors and quality of life: a critical review of the literature. *Oncology Nursing Forum* **27**, (9), 1395-1401.
- Zebrack B. (2001) An advocate's perspective on cancer survivorship. *Seminars in Oncology Nursing* **17**, (4), 284-287.
- Zebrack B. J., Yi J., Petersen L. & Ganz P. A. (2008) The impact of cancer and quality of life for long-term survivors. *Psycho Oncology* **17**, (9), 891-900.

APPENDICES

Appendix 1: Ethical approval letter

Please quote ref no: **D/06/2010**

Direct line/e-mail
+44 (0) 115 8231063
Louise.Sabir@nottingham.ac.uk

Professor Karen Cox
Professor of Cancer & Palliative and End of Life Studies
School of Nursing, Midwifery and Physiotherapy
B Floor, The Medical School
QMC Campus
Nottingham University Hospitals
Nottingham
NG7 2UH

22nd June 2010

Dear Professor Cox

Ethics Reference No: D/06/2010 - Please quote this number on all correspondence

Study Title: The experience of long-term cancer survivorship: a multiple case study.

Lead Investigator: Professor Karen Cox, Professor of Cancer & Palliative and End of Life Studies

Co Investigators: Ms Emma Blows, PhD Student, School of Nursing, Midwifery and Physiotherapy, Professor Jane Seymour, Sue Ryder Care Professor of Palliative and End of Life Studies, School of Nursing Midwifery and Physiotherapy.

Thank you for submitting the above application which was considered at the Medical School Research Ethics Committee at its meeting on 17th June 2010. The following documents were reviewed:

- Application form 6/1/2010
- Project proposal dated 1/06/2010
- Information sheet for cancer survivors v1 14/04/2010
- Information sheet for partner/carer v1 dated 14/04/2010
- Interview schedule dated 1/06/2010
- Recruitment Poster dated 01/06/2010
- E-mail to support groups dated 01/06/2010
- Volunteer consent form v1 dated 01/06/10
- Letter to be sent out with information sheet (cancer survivors) dated 01/06/2010
- Letter to be sent out with information sheet (Significant other) dated 01/06/2010
- Decline letter dated 01/06/2010
- Pre interview Screening crib sheet dated 01/06/2010
- Reply slip for volunteers
- Significant other nomination form dated 01/06/2010
- Risk assessment form

The Committee was pleased to review this well thought out project and this study was approved.



Faculty of Medicine and Health Sciences

Medical School Research Ethics Committee
Division of Therapeutics & Molecular Medicine
D Floor, South Block
Queen's Medical Centre
Nottingham
NG7 2UH

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Fax: +44 (0) 115 8231059

We particularly liked the way you had addressed the ethical issues and also the issues of lone researchers.

Approval is given on the understanding that the Conditions of Approval set out below are followed.

Conditions of Approval

You must follow the protocol agreed and any changes to the protocol will require prior Ethic's Committee approval.

This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.

You promptly inform the Chairman of the Ethic's Committee of

- (i) Deviations from or changes to the protocol which are made to eliminate immediate hazards to the research subjects.
- (ii) Any changes that increase the risk to subjects and/or affect significantly the conduct of the research.
- (iii) All adverse drug reactions that are both serious and unexpected.
- (iv) New information that may affect adversely the safety of the subjects or the conduct of the study.
- (v) The attached End of Project Progress Report is completed and returned when the study has finished.

Yours sincerely



Professor R C Spiller
Chairman, Nottingham University Medical School Ethics Committee

Appendix 2: Letter to Ethics Committee requesting change to research protocol

9th August 2010

Dear Professor Spiller

Ethics Reference No: D/06/2010

The experience of long-term cancer survivorship: a multiple case study

I am writing to request a change to the protocol for the above approved study.

The ethics application states that the study location is South West London (specifically, the boroughs of Richmond, Kingston, Hounslow and Wandsworth) (p3). The information and recruitment materials also highlight that participants should live in one of the 4 boroughs. These boroughs were chosen because their levels of deprivation vary (socioeconomic status is a variable of interest in the study), but also for practical reasons (the researcher lives in SW London).

However, having sent out recruitment materials, it is evident that basing the study in just these boroughs may prove restrictive. Participants that meet all but the domicile criterion have registered their interest. They tend to live in other parts of London or the home-counties (e.g. Bucks).

Therefore, we propose that the focus of recruitment continues to be SW London, approaching cancer support/community groups in the four boroughs of interest. However, if potential participants approach us from outside these boroughs, they will be considered for inclusion in the study. A decision as to whether they can be included will be based, in part, on whether a suitable interview location can be found that is within a reasonable travel distance for the participant and researcher, but also whether the sample includes those of varying socioeconomic status.

As a result of this proposed change, the information and advertising materials will need a minor modification. The inclusion criteria will state that participants: *Ideally* live in the South West London boroughs of Hounslow, Richmond, Wandsworth or Kingston.

If you require any further information regarding the proposed change, please do not hesitate to contact me.

I look forward to hear the outcome of our proposed change in due course.

Yours sincerely

Emma Blows
PhD Researcher; ntxeb5@nottingham.ac.uk

Appendix 3: Ethical approval letter regarding change to protocol

Direct line/e-mail
+44 (0) 115 8231063
Louise.Sabir@nottingham.ac.uk



12 August 2010

Professor Karen Cox
Professor of Cancer & Palliative and End of Life Studies
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Dear Professor Cox

Ethics Reference No: D/06/2010 - Please quote this number on all correspondence

Study Title: The experience of long-term cancer survivorship: a multiple case study.

Lead Investigator: Professor Karen Cox, Professor of Cancer & Palliative and End of Life Studies

Co Investigators: Ms Emma Blows, PhD Student, School of Nursing, Midwifery and Physiotherapy, Professor Jane Seymour, Sue Ryder Care Professor of Palliative and End of Life Studies, School of Nursing Midwifery and Physiotherapy.

Thank you for your letter dated 9th August informing the Committee of an amendment to the inclusion criterion of the above study as follows:

- Change of wording to the information and advertising materials: the inclusion criteria will now state that participants: *Ideally* live in the South West London Boroughs of Hounslow, Richmond, Wandsworth or Kingston. This will enable inclusion of participants that meet all but the domicile criterion who have already approached and registered an interest and future potential participants to do so.

These have been reviewed and are satisfactory and the study amendment is noted and approved.

Approval is given on the understanding that the Conditions of Approval set out below are followed.

Conditions of Approval

You must follow the protocol agreed and any changes to the protocol will require prior Ethic's Committee approval.

This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.

You promptly inform the Chairman of the Ethic's Committee of

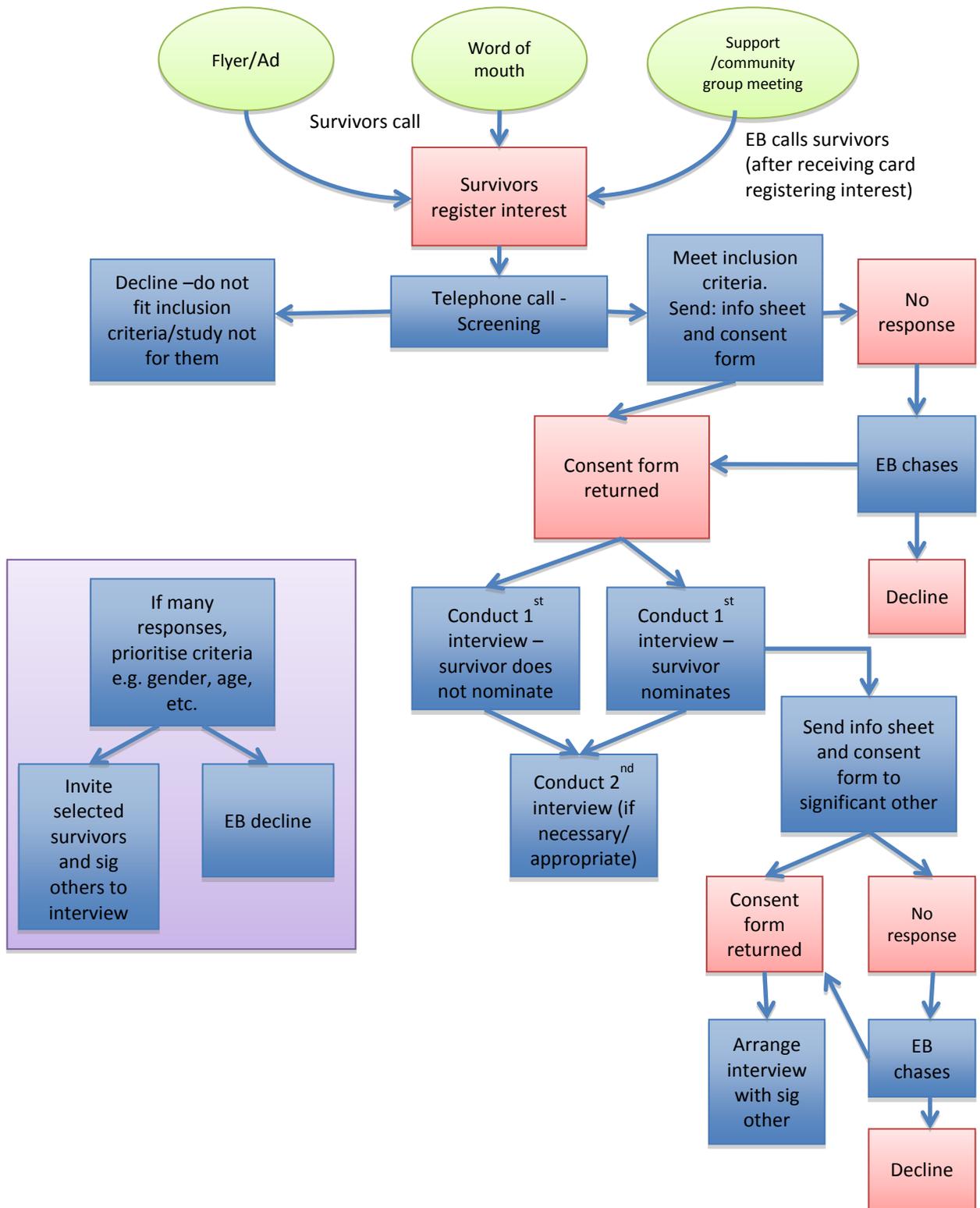
- (i) Deviations from or changes to the protocol which are made to eliminate immediate hazards to the research subjects.
- (ii) Any changes that increase the risk to subjects and/or affect significantly the conduct of the research.
- (iii) All adverse drug reactions that are both serious and unexpected.
- (iv) New information that may affect adversely the safety of the subjects or the conduct of the study.
- (v) The attached End of Project Progress Report is completed and returned when the study has finished.

Yours sincerely

A handwritten signature in purple ink, appearing to read 'R C Spiller', is written in a cursive style.

Professor R C Spiller
Chairman, Nottingham University Medical School Research Ethics
Committee

Appendix 4: Recruitment diagram



Appendix 5: Recruitment Flyer



Research study on the experience of long-term cancer survivorship

The School of Nursing, Midwifery and Physiotherapy at the University of Nottingham and Macmillan Cancer Support are looking to interview 20 cancer survivors to explore their experience of living some time after diagnosis and treatment.

Participants will be asked to take part in up to 2 interviews, each lasting around 2 hours, exploring questions such as:

- What does cancer mean to you now?
- What impact has cancer had on you and your relationships?
- What do you do to manage day-to-day living with cancer?

To take part, participants must meet the following criteria:

- Adults over the age of 23
- Diagnosed with breast, prostate, bowel, gynaecological, testicular, bladder cancer or Hodgkin's Lymphoma
- Completed hospital-based treatment (surgery, chemotherapy and/or radiotherapy) **at least 5 years ago**
- Free from cancer (the cancer has not come back, you have not been diagnosed with a second cancer and the cancer has not spread to another part of the body)
- Live in the London boroughs of Hounslow, Richmond, Wandsworth or Kingston
- Able to communicate in English

For further information, please contact:

Emma Blows, PhD Researcher
Tel: 07921859135
Email: ntxeb5@nottingham.ac.uk

This study is funded by the Economic and Social Research Council and Macmillan Cancer Support and has been approved by the University of Nottingham Medical School Ethics Committee.

Appendix 6: Letter to interested participants



Date

Dear xxxx

The experience of long-term cancer survivorship: a multiple-case study

Thank you for your interest in taking part in a study exploring experiences of cancer survivorship.

Please find enclosed further information on what the study is about, and what taking part would involve.

I have also enclosed a consent form. If, once you have read the information sheet, you think that you would like to take part, please sign the consent form and send it back to me, either by post or email (details below).

It will only be possible to interview a maximum of 20 people so I cannot guarantee that everyone who is interested in taking part in the study will be able to. Once I have received your form, I will contact you to let you know whether or not we can go ahead with an interview.

In the meantime, if you have any further questions about the study, please do not hesitate to contact me.

Thank you again for your interest in the study.

Yours sincerely

A handwritten signature in black ink that reads 'Emma Blows'.

Emma Blows
PhD Researcher

Tel: 07921859135
Email: ntxeb5@nottingham.ac.uk

Appendix 7: Example Decline Letter



The University of
Nottingham

The experience of long-term cancer survivorship: a multiple-case study

DATE

Dear xxxx

Thank you for returning the consent form for our study exploring experiences of cancer survivorship.

Unfortunately, I am unable to invite you take part in the study. As I can only interview 20 people, it has not been possible to invite everyone interested in the study to take part.

If you have any queries regarding this letter/email, or the study more generally, please do not hesitate to contact me.

Thank you again for your interest in the study.

With best wishes

A handwritten signature in black ink that reads 'Emma Blows'.

Emma Blows
PhD Researcher

Tel: 07921859135

Email: ntxeb5@nottingham.ac.uk

Appendix 8: Information Sheet (survivors)



The University of
Nottingham

The experience of long-term cancer survivorship: a multiple-case study

Name of Investigators:

Emma Blows, PhD Researcher
Professor Karen Cox (Supervisor)
Professor Jane Seymour (Supervisor)

Healthy Volunteer's Information Sheet

Thank you for registering your interest in taking part in a research study exploring the experience of being a long-term cancer survivor. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish to. Ask us if there is anything that is not clear or if you would like more information. Take the time to decide whether you wish to take part or not.

If you decide to take part, you will be given a copy of this information sheet and a signed consent form to keep.

Background

With more people surviving a diagnosis of cancer, it is important to understand what life is like for those living with cancer and its effects.

This study aims to explore the experiences of people diagnosed with, and treated for, cancer some time ago. For this study, this means people who finished hospital-based treatment (surgery, radiotherapy and/or chemotherapy) over five years ago.

We would like to hold interviews with cancer survivors and those close to them (selected by cancer survivors themselves), to explore questions such as:

- What does cancer mean to you now?
- What impact has cancer had on you and your relationships?
- What do you do to manage day-to-day living with cancer?

The interviews will be developed into case studies, which will outline the experiences described by participants. The findings will then be used to make

recommendations for cancer services and policy developments aimed at improving the quality of life for cancer survivors and those close to them.

Preliminary work on the study began in 2009. Data collection will take place between September 2010 and September 2011. Findings and a final report will be available in Autumn 2012.

What does the study involve?

You will be involved in the research over a period of approximately 3-4 weeks. You will be asked to take part in up to 2 interviews, the first lasting up to 2 hours, and the second, a follow-up interview, about 3 weeks later, which could also last up to 2 hours. The second interview is optional but it would give us the opportunity to explore further some of your responses from the first interview. It will also help us check anything we are unclear of. The interviews are likely to take place in a private room somewhere in the local community (such as a community centre, library, etc.). However, if this is not appropriate, an alternative location can be arranged.

You will be asked to describe your experience of living some time after diagnosis and treatment for cancer. This will probably include talking, in your own words, about what cancer means to someone diagnosed some time ago, what impact cancer has had on you and your relationships, and things you might do to manage daily living with cancer.

The focus will be on you to tell your story in your own words. The researcher will start you off with quite a broad question such as: tell me about your experience of living some time after a cancer diagnosis? After that, it will be up to you what you talk about with regard to your experiences. The researcher may probe for further details at certain points, but the majority of the talking will be done by you. This type of interview is known as a narrative interview as the focus is on you to tell your story in your own words and in your own way.

In addition, with your consent, we would like to talk to someone close to you (such as a partner, relative, or friend) who has helped/supported you during your cancer experience. At the end of the first interview, we would like you to suggest a person for us to interview once, face-to-face for up to 2 hours. We would discuss with them what impact they feel cancer has had on you, and your relationship with them.

If you are able to suggest someone close to you to take part in an interview, we will give you a nomination form at the end of first interview. Please discuss this with the person you plan to nominate before you put their name forward. We will then contact them separately to see whether they would like to take part in the study.

If you do not want us to interview someone close to you, that is fine. It will not impact on whether you can take part in the study.

Why have you received this information?

You have received this information sheet after contacting us to register your interest in taking part in the study. You may have heard about it from a community/support group or voluntary organisation, or from someone else who has taken part.

There are certain criteria that you will need to meet to be able to take part in the study:

- An adult over the age of 23
- Have been diagnosed with breast, prostate, bowel, gynaecological, testicular, bladder cancer or Hodgkin's Lymphoma
- Completed hospital-based treatment (surgery, chemotherapy and/or radiotherapy) at least 5 years ago
- Free from cancer i.e. your cancer has not come back, you have not been diagnosed with a second cancer and the cancer has not spread to another part of the body
- Ideally live in the South West London boroughs of Hounslow, Richmond, Wandsworth or Kingston
- Able to communicate in English

As it is only possible to interview up to 20 people (and those close to them), not everyone interested in taking part in the study will be interviewed. If it is not possible to interview you, you will receive a letter informing you as such. If it is possible, we will contact you by telephone or email to arrange a date and time for the first interview.

Do you have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What do I have to do?

You will be invited to take part in up to two interviews where we will explore your experience of living for some time after a cancer diagnosis. The first interview is likely to take up to 2 hours. The follow-up interview is likely to be of a similar length and will be used to clarify any points that were unclear in the first interview and give you the opportunity to provide any further details about your experience. Please note that interview times may vary from interview to interview.

The interviews will be conducted face-to-face with Emma Blows, who is a PhD Researcher with 4 years experience conducting research with people affected by cancer.

What are the possible disadvantages and risks of taking part?

Talking about your cancer experience may be quite emotional and upsetting at times. If you feel yourself becoming upset in the interview, you will be able to stop at any time and start again when you feel ready. If it continues to be too upsetting, you can withdraw from the study at any time, with no need for an explanation.

Details on local information and support services for people affected by cancer will be available, including Macmillan Cancer Support's helpline: 0808 808 0000. If necessary, we may suggest you contact your GP for further advice.

What if something goes wrong/who can I complain to?

In case you have a complaint on your treatment by a member of staff or anything to do with the study, you can initially approach the lead investigator:

Professor Karen Cox, Professor of Cancer & Palliative Care, Pro Vice Chancellor, Human Resources, Access & Community, A5 Trent Building, University Park, Nottingham, NG7 2RD. Telephone 0115 8232480. Email karen.cox@nottingham.ac.uk

If this achieves no satisfactory outcome, you should then contact the Ethics Committee Secretary: Mrs Louise Sabir, Division of Therapeutics and Molecular Medicine, D Floor, South Block, Queen's Medical Centre, Nottingham, NG7 2UH. Telephone 0115 8231063. E-mail louise.sabir@nottingham.ac.uk

Will my taking part in this study be kept confidential?

In accordance with the current Data Protection Act, all information which is collected about you during the course of the research will be kept on a password protected computer and is strictly confidential. Any information about you which leaves the research unit will have your name and address removed so that you cannot be recognised from it. Any quotes used in reports, conference presentations or publications will be anonymised and cannot be traced to you.

What will happen to the results of the research study?

The results from the study will go towards Emma Blows's PhD thesis. Papers will also be written for publication in journals and presentations made at conferences, based on the findings from this research. You will not be identified in any report or publication. All quotes will be anonymised.

Recommendations from the study will inform Macmillan Cancer Support's service and policy developments.

The thesis is due to be submitted in Autumn 2012. If you would like a copy of the research findings, please indicate your wish to do so during the interview.

Who is organising and funding the research?

The study is funded by an Economic and Social Research Council (ESRC) CASE studentship. The ESRC is a government-funded research council. What this means is that the ESRC has provided funds for the University of Nottingham to undertake this research. Funds are also provided by Macmillan Cancer Support, a UK voluntary organisation providing support and campaigning for improved care for people affected by cancer. Macmillan Cancer Support is working with University of Nottingham researchers on this study.

Who has reviewed the study?

This study has been reviewed and approved by the University of Nottingham Medical School Ethics Committee.

Contact for further information

Emma Blows, PhD Researcher
Email: ntxeb5@nottingham.ac.uk
Tel: 07921859135
Address:
B49, South Block Link
Queen's Medical Centre
Nottingham, NG7 2HA

Thank you for your interest in taking part in the study.

Appendix 9: Information Sheet (significant others)



The University of
Nottingham

The experience of long-term cancer survivorship: a multiple-case study

Name of Investigators:

Emma Blows, PhD Researcher
Professor Karen Cox (Supervisor)
Professor Jane Seymour (Supervisor)

Healthy Volunteer's Information Sheet

Thank you for registering your interest in taking part in a research study exploring the experience of long-term cancer survivorship. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you wish to. Ask us if there is anything that is not clear or if you would like more information. Take the time to decide whether you wish to take part or not.

If you decide to take part, you will be given a copy of this information sheet and a signed consent form to keep.

Background

With more people surviving a diagnosis of cancer, it is important to understand what life is like for those living with cancer and its effects.

This study aims to explore the experiences of people diagnosed with, and treated for, cancer some time ago. For this study, this means people who finished hospital-based treatment (surgery, radiotherapy and/or chemotherapy) at least 5 years ago.

We would like to hold interviews with cancer survivors and those close to them (selected by cancer survivors themselves), to explore questions such as:

- What does cancer mean to survivors now?
- What impact has cancer had on the cancer survivor and their relationships?
- What survivors and those close to them do to manage day-to-day living with cancer?

The interviews will be developed into case studies, which will outline the experiences described by participants. The findings will then be used to make recommendations for cancer services and policy developments aimed at improving the quality of life for cancer survivors and those close to them.

Work on the study began in 2009. Data collection will take place between September 2010 and September 2011. Findings and a final report will be available in Autumn 2012.

What does the study involve?

You will be asked to take part in 1 face-to-face interview, lasting up to 2 hours. Ideally, you will be interviewed separately to the person previously diagnosed with cancer. The interview is likely to take place in a private room somewhere in the local community (such as a community centre, library, etc.). However, if this is not appropriate, an alternative location can be arranged.

You will be asked to describe your experience of supporting a cancer survivor. This will probably include talking, in your own words, about X's experience of being a cancer survivor and the impact cancer has had on your lives. The focus will be on you to tell your story in your own words. The researcher will start off with quite a broad question such as: can you tell me about what effect you think cancer has had on X and your relationship with them? After that, it will be up to you what you talk about with regard to your experiences. The researcher may probe for further details at certain points, but the majority of the talking will be done by you. This type of interview is known as a narrative interview as the focus is on you to tell your story in your own words and in your own way.

Why have you been chosen?

You have received this information sheet as a result of being nominated by X. X felt you would be a good person to speak to about their experience of cancer, and the impact it has had on your relationship with them.

There are certain criteria that you have to meet to be able to take part in the study:

- An adult over the age of 23
- Able to communicate in English
- Ideally, live in the South West London boroughs of Hounslow, Richmond, Wandsworth or Kingston, although if you live outside London a telephone interview may be possible

Do you have to take part?

It is up to you whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form.

If you decide to take part you are still free to withdraw at any time and without giving a reason.

What do I have to do?

You will be invited to take part in a one-to-one interview where we will explore your experience of supporting some diagnosed with cancer. The interview is likely to take up to 2 hours. However, please note times may vary from interview to interview.

The interview will normally be conducted face-to-face with Emma Blows, who is a PhD Researcher with 4 years experience conducting research with people affected by cancer.

What are the possible disadvantages and risks of taking part?

Talking about the cancer experience of someone close to you, and the impact it has had on them and your relationship, may be quite emotional and upsetting at times. If you feel yourself becoming upset in the interview, you will be able to stop at any time and start again when you feel ready. If it continues to be too upsetting, you may withdraw for the study at any time, with no need for an explanation.

Details on local information and support services for people affected by cancer will be available, including Macmillan Cancer Support's helpline: 0808 808 0000. If necessary, we may suggest you contact your GP for further advice.

What if something goes wrong/who can I complain to?

In case you have a complaint on your treatment by a member of staff or anything to do with the study, you can initially approach the lead investigator:

Professor Karen Cox, Professor of Cancer & Palliative Care, Pro Vice Chancellor, Human Resources, Access & Community, A5 Trent Building, University Park, Nottingham, NG7 2RD. Telephone 0115 8232480. Email karen.cox@nottingham.ac.uk

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Will my taking part in this study be kept confidential?

In accordance with the current Data protection Act, all information which is collected about you during the course of the research will be kept on a password protected computer and is strictly confidential. Any information about you which leaves the research unit will have your name and address removed so that you cannot be recognised from it. Any quotes used in reports, conference presentations or publications will be anonymised and cannot be traced to you.

What will happen to the results of the research study?

The results from the study will go towards Emma Blows' PhD. Papers will also be written for publication in journals and presentations made at conferences, based on the findings from this research. You will not be identified in any report or publication. All quotes will be anonymised.

Recommendations from the study will inform Macmillan Cancer Support's service and policy developments.

The thesis is due to be submitted in Autumn 2012. If you would like a copy of the research findings, please indicate your wish to do so at the end of the interview.

Who is organising and funding the research?

The study is funded by an Economic and Social Research Council (ESRC) CASE grant. The ESRC is a government-funded research body. What this means is that the ESRC has provided funds for the University of Nottingham to undertake this research. Funds are also provided by Macmillan Cancer Support, a UK voluntary organisation providing support and campaigning for improved care for people affected by cancer. Macmillan Cancer Support is working with University of Nottingham researchers on this study.

Who has reviewed the study?

This study has been reviewed and approved by the University of Nottingham Medical School Ethics Committee.

Contact for further information

Emma Blows, PhD Researcher
Email: ntxeb5@nottingham.ac.uk
Tel: 07921859135
Address:
B49, South Block Link
Queen's Medical Centre
Nottingham, NG7 2HA

Thank you for your interest in taking part in the study.

Appendix 10: Initial Screening Crib Sheet

School of Nursing, Midwifery and Physiotherapy, Division of Nursing

Experience of long-term cancer survivorship Screening crib sheet

Participant ID:

Name:

Address:

Postcode:

[EB – in catchment? Y/N]

[EB – SES? High/Low]

Telephone number:

Email:

Gender:

Male Female

Age:

[EB – over 23? Y/N]

Type of cancer:

[EB – Y/N]

Diagnosed (month/year):

Finished hospital-based treatment (month/year):

[EB - ≥5 years? Y/N]

Disease free?

[EB = Y/N]

Do they meet inclusion criteria?

YES NO

How did they hear about the study?

Cancer support grp/org
Community grp (*specify*)
Friend/relative
Other (*specify*)

How do they prefer to be contacted?

Telephone
Post
Email

Additional information

Told them about information sheet, consent form and nomination? YES NO

Told them that not everyone interested will be able to take part? YES NO

Send information sheet and consent form? YES NO

Date:

Declined?

EB Participant

(This information kept separate from data collected during interviews, etc.)

Appendix 11: Consent form



The University of
Nottingham

The experience of long-term cancer survivorship

Investigators: Emma Blows; Professor Karen Cox; Professor Jane Seymour

Healthy Volunteer's Consent Form

Please read this form and sign it once the above named, or their designated representative, has explained fully the aims and procedures of the study to you.

- I voluntarily agree to take part in this study.
- I confirm that I have been given a full explanation by the above named and that I have read and understand the information sheet given to me which is attached.
- I have been given the opportunity to ask questions and discuss the study with one of the above investigators on all aspects of the study and have understood the advice and information given as a result.
- I agree to the above investigators contacting my general practitioner to make known my participation in the study where relevant.
- I agree to comply with the reasonable instructions of the supervising investigator and will notify her immediately of any unexpected unusual symptoms or deterioration of health.
- I authorise the investigators to disclose the results of my participation in the study but not my name.
- I understand that information about me audio recorded during the study will be kept in a secure database. If data is transferred to others it will be made anonymous. Data will be kept for 7 years after the results of this study have been published.
- I understand that I can ask for further instructions or explanations at any time.
- I understand that I am free to withdraw from the study at any time, without having to give a reason for withdrawing.
- I confirm that I have disclosed relevant medical information before the study.

Name:.....

Address:.....

Telephone number:.....

Signature:.....

Date:.....

To be filled in by the researcher:

I confirm that I have fully explained the purpose of the study and what is involved to:

.....

I have given the above named a copy of this form together with the information sheet.

Investigator's Signature:.....

Investigator's Name:.....

Date:.....

Participant ID:.....

**Appendix 12: 'Significant other' Nomination
Letter and Form**



School of Nursing, Midwifery and Physiotherapy, Division of Nursing

**Experience of long-term cancer survivorship
Nomination Form**

It is often the case that cancer does not affect the person diagnosed alone, but impacts on family, friends, colleagues, etc. To fully explore experiences of cancer survivorship, we would like to interview someone who has supported you during your cancer experience. If possible, we would like you to suggest someone close to you (e.g. partner, relative, friend, etc.) who might be willing to take part in an interview to discuss how they feel cancer has affected you and your relationship with them.

If you would like to nominate someone, please discuss it with them first and then fill in their details below. I will then contact your nominated person to discuss the study further.

If you would prefer not to nominate somebody, that's absolutely fine.

If you have any questions or concerns about this part of the study, please do not hesitate to contact me. Further details can also be found on the information sheet.

Thank you very much.

A handwritten signature in black ink that reads 'Emma Blows'.

Emma Blows
PhD Researcher



The University of
Nottingham

Nomination Form: Interview with someone close to you

Your name: _____

Would you be willing for us to interview someone close to you who has supported you through your cancer experience?

Yes No

If yes, please give details of the person you would like us to contact
(NB: please make sure you have discussed the study with this person before you put their name forward)

Name: _____

Relationship to you: _____

Contact details: (telephone and/or email)

Thank you for taking the time to fill in this form.

Appendix 13: Interview schedule (survivors)

Narrative interview

Introduction at the start of the narrative interview

Ask a broad, open-ended question to start - allows you to share your experiences in their own way. However, there are some broad areas I want to cover, so I may prompt for further details. Flexible - some people feel comfortable talking about their experiences but others need a bit more prompting.

Interested in: the meaning and place of cancer in your life now; and the impact it has had, and may continue to have, on you and your relationships. Not an exhaustive list so feel free to share your experiences as you wish.

Interview could last up to 2 hours but how long it lasts is very much dependent on the individual so we will just see how it goes.

Emotive topic - if at any point you want to pause the interview, please feel free to do so. Also if you continue to find it too distressing, we can stop the interview altogether and you can withdraw from the study without having to give a reason.

Any questions about anything we've covered so far?

Before we start, can you tell me a little bit about yourself? (Background not picked up in the initial telephone conversation).

Questions to 'induce narrative'

Taking you back first of all, can you tell me about your experiences of diagnosis and treatment? You can start the story where you want. You are free to talk about it in whatever way you choose. I'll go back and ask you more specific questions in the areas where I want to know more.

Bringing you forward now, could you tell me about your experience of life post-treatment. I'm interested in what life has been like for you since you completed treatment and in particular what life is like for you now?

Follow-up interview – areas to probe

FOCUS: Reflect on everyday life, how cancer is affecting them now, and why

1. The meaning of cancer now (and whether it has changed over time)

E.g. Have you spent time trying to figure out why cancer happened to you?

2. How they perceive themselves, and how they feel others perceive them, as a result of cancer.

E.g. What do you think of the term 'cancer survivor'? Do you think of yourself as such?

3. The impact cancer has had on their life e.g. changing behaviour, goals, personal characteristics, philosophy

4. The impact cancer has had on close relationships; responses of others to their cancer

5. Strategies used to cope with/manage the cancer experience into their day-to-day lives

E.g. How have you gotten through this experience? What has been helpful? What has not been helpful? What is helpful now?

Indicate coming to the end - final questions:

What place does cancer have in your life now? What does the future look like?

At the end: How did it feel taking part? What motivated you to take part?

Nomination form

Appendix 14: Interview schedule (significant others)

Introduction at the start of the interview

Ask a broad, open-ended question to start - allows you to share your experiences in their own way. However, there are some broad areas I want to cover, so I may prompt for further details. Flexible - some people feel comfortable talking about their experiences but others need a bit more prompting.

Interested in: your experiences relating to the impact you feel cancer has had on X and your relationship with them.

Interview could last up to 2 hours but how long it lasts is very much dependent on the individual so we will just see how it goes.

Emotive topic - if at any point you want to pause the interview, please feel free to do so. Also if you continue to find it too distressing, we can stop the interview altogether and you can withdraw from the study without having to give a reason.

Any questions about anything we've covered so far?

Before we start, can I just take down a few more background details, just to help gain a better profile for the case study.

Questions to 'induce narrative'

What I'm really interested in is hearing your perspective about the impact you feel X's diagnosis has had on them and also on your relationship with them. Really it's an opportunity for you to tell me, in your own words and in your own way, how you think it's affected X and what place cancer has in your lives today.

So perhaps if you could start by telling me a bit about your experiences of X's cancer and then I'll ask you some more specific questions in the areas where I want to know more later in the interview.

Areas to prompt/probe

FOCUS: Getting people to reflect on their everyday life, how cancer is affecting the person diagnosed with cancer now and why?

- 1. The impact they feel cancer has had on the person diagnosed with cancer**

How would you have described X before cancer? How would you describe X now? How do you think X would have described themselves before cancer? And now?

How did they feel at the 5-year marker? How did you feel?

How has cancer changed how X sees the world and what they believe is important?

How do you think the experience of having cancer has affected the way in which X currently views life?

2. The meaning they feel cancer holds for the person diagnosed with cancer now (and whether this has changed over time)

Has X spent time trying to figure out why cancer happened to them? [Do you think they still spend time doing this?]

How much time did X spend searching to make some sense or find some meaning in the experience? [Do they still do this?]

3. The impact cancer has had on their relationship

How do you think you have responded to their cancer? At diagnosis and during treatment? And now?

What things are different about life now than before X had cancer?

How, as a couple, have you gotten through this experience? What has been helpful? What has not been helpful?

4. The impact cancer has on their lives now

Do you feel you have gained or lost anything?

How much good has come out of X having cancer? How much harm has come out of it? For X, and in terms of your relationship.

What place does cancer have in X's life now? And for you as a couple, how does it affect your lives now?

Indicate coming to the end - final questions:

How do you think X views the future?

What does the term 'the future' mean to you now?

Appendix 15: Summary Narrative Assessment (SNA) Template

CASE STUDY 1: SUE

Key quotes from narrative

Sue's story

- Socio-demographic and cancer-related information
- Outline experience of long-term survivorship

Survivorship trajectory diagram

Perception of cancer and its causes

Key events in the long-term survivorship phase

Life events/context

Day-to-day impact of cancer

Identity

- Who was Sue prior to cancer? Who is Sue today?
- How Sue thinks others perceive her now
- Cancer identity

Relationships and interactions

E.g. With healthcare professionals; partner/family, work, friends, cancer charities, other people with cancer, etc.

Coping strategies

Place of cancer today

Triggers/reminders of cancer

Benefits and losses

The future

'Significant other' interview (if applicable)

My description of Sue's experience of long-term cancer survivorship

- Type of narrative – how I defined Sue's story. Underlying theme(s).
- How I responded to Sue's narrative