Living With and Beyond Cancer:
A study to investigate what it is like
to live with and beyond a 'poor prognostic' cancer
in contemporary society.

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**A thesis submitted in fulfilment of
the requirements for the degree of
Doctor of Philosophy in Health Sciences**

**Warwick Medical School
University of Warwick**

November 2012

For my Dad

who always had faith in me

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Acknowledgements

This work would not have been possible without the kindness and support of many people. I am very grateful to everyone who has helped me along the way and would like to personally thank the following:

Firstly, and very importantly, the study participants who have generously given up their time to tell me their stories and take their photographs with candour, humour and courage.

My colleagues and professional associates throughout the UK who have backed my work and assisted the (mostly) smooth running of this study.

My PhD supervisors, Professor Janet Dunn and Professor Frances Griffiths, for their guidance, counsel, inspiration and for sharing their wealth of knowledge with me.

The West Midlands Strategic Health Authority for awarding me a Nurse, Midwife and Allied Health Professional Research Training Fellowship, which has given me the financial backing necessary to complete this work.

All my loyal and long-suffering friends for their wonderful camaraderie and constant reassurance.

My brothers, Howard and Guy, and sisters-in-law, Tam and Lucy, who have always supported and encouraged me tremendously. My nieces, Willow, Martha, Beatrice and Eleanor and my nephew, Beck, who have made me laugh and put things into perspective.

My Mum and Dad. Very sadly, neither of them finished this particular journey with me but, if it wasn't for the belief they always had in me, the encouragement they continually gave me and the love of learning and tenacity they left for me, I would never have finished – or started - this endeavour.

Finally, a huge thank you to my boyfriend, then my partner, now my husband, John Doré, for his unrelenting care, support, kindness, generosity, patience and love throughout.

Declaration

This thesis is my own original work and has not been published elsewhere or submitted to

any other institute of higher education for the award of a degree,

other than the University of Warwick.

Abstract

In the UK, more than two million people are alive following a cancer diagnosis and people with cancer live an average six times longer than they did forty years ago. There have been dramatic survival improvements in some cancers with six now having median survival expectations of over ten years. This is remarkable but cancer consists of more than two hundred 'types' and, for some types, predicted survival is still only weeks. Furthermore, some issues related to long term survival are only just emerging, many remain under-researched and studies that exist have been criticised for being drawn from limited cancer sites and ignoring the coping strategies and social contexts of those diagnosed with cancer.

The aim of this work is to explore the experience of living with and beyond the diagnosis of a 'poor prognostic' cancer in contemporary society and from a sociological perspective.

The work is informed by a literature review which explores lay understanding of cancer, a theoretically driven investigation designed to produce a sociological understanding of what it is like to live with cancer, a feasibility study and a full empirical study, which were both supported by users. Data for the principal study was generated by 'photovoice'; a novel participatory method in which participants created and discussed photographs to illustrate and describe their experience in depth.

This study revealed that living with and beyond cancer was an ongoing disruptive experience for participants and their constant fear of recurrence impacted on future plans. Furthermore, society's stigmatising perception of cancer bestowed certain responsibilities and obligations on the participants. Photographs added a power and richness to the data.

This work adds to the very limited understanding of the experience of cancer and 'survivorship' for this group and will hopefully guide appropriate communication, service provision and future research.

Chapter 1

Introduction

There are more than two million people living with or after a cancer diagnosis in the UK today and this figure is rising by 3.2% every year. In the past thirty-five years, median cancer survival time has improved from one to 5.8 years and one and a quarter million people are alive for more than five years after a cancer diagnosis (Glaser 2011, Macmillan Cancer Support 2011). This is very positive news about something that has been described as 'the killer disease' (Sontag 1991, p59) and 'a lethal shape-shifting entity' (Mukherjee 2011, pxiii). But what is it like to be a 'cancer survivor'? When treatment is over do people 'get back to normal' or are they always defined by this common disease that seems to hold an unprecedented metaphorical, scientific, cultural and political potency and be so feared that some people still refer to it as the 'Big C' (Stacey 1997, Diamond 1999, Mukherjee 2011).

In particular, as a nurse who has worked for much of my career with people who have had cancers with likely poor prognoses (e.g. ovarian and lung) and with an interest in the social and cultural representation of cancer (Balmer 2005), I have often wondered what it must mean to be defined as a 'cancer survivor' for the many people who are still expected *not* to survive for very long? The celebrated and often cited positive statistics conceal inconsistent progress. There is a huge disparity in survival rates between cancer 'types', with some achieving dramatic improvements while others have made hardly any progress at all. For instance, there has been a seventeen fold increase in colon cancer survival, from a median survival of seven months in the 1970s to ten years today but, in the same time, lung cancer survival has risen from only eleven to twenty weeks and pancreatic cancer survival has risen from just nine to twelve weeks (Macmillan Cancer Care 2011).

Putting the research into context: UK cancer facts and figures

In 2008 (latest available annual incidence figures) there were more than 300,000 new cases of cancer in the UK (excluding non-melanoma skin cancer) which were responsible for 28% of all deaths. Although over two hundred types of cancer exist, four (breast, lung, colorectal and prostate) account for more than 54% of new cases. Cancer is predominantly a disease of older age with 36% of cases diagnosed in people older than seventy-five and only 0.5% in children under fourteen years (Cancer Research UK 2011[E]).

Reflecting its incidence, cancer causes greater mortality in older age, with 77% of cancer deaths occurring in people older than sixty-five. Lung cancer has the highest mortality in both men and women (Cancer Research UK 2011[E]). In general, men are at significantly greater risk than women of both developing and dying from all the common cancers that occur in both sexes, with the exception of breast cancer (National Cancer Intelligence Network 2009[B]). Although people from black and minority ethnic groups are at a lower risk overall from cancer, there is an increased risk and lower survival rate of certain cancers in some ethnic groups (National Cancer Intelligence Network and Cancer Research UK 2009[A]).

Cancer survival statistics are usually presented as relative survival at five years after diagnosis (Cancer Research UK 2009[A]). Overall, the five-year relative survival rate for cancer in the UK is 50% with a slightly higher rate in women than men (56% v 43%). However, increased survival is not universal throughout the spectrum of cancer sites. For example, breast cancer now has a five year survival rate of 82% in England (Cancer Research UK 2009[B]) whereas the survival rate for pancreatic cancer is only 3% (Cancer Research UK 2010[C]).

Among adults, survival decreases with increasing age at diagnosis for almost every cancer, despite the higher mortality from other causes in older people being factored in. Survival is lower in more deprived populations, even after allowing for the higher mortality generally in such groups. One of the aims of the NHS Cancer Plan (2000) was to reduce inequalities in cancer survival between the wealthier and less privileged groups in society. In general, cancer survival improved during the 1990s but the gap between the most affluent and deprived groups also increased for most cancers and was wider for patients diagnosed in the late 1990s compared to the late 1980s (Coleman et al 2004). Closing this gap could prevent over 3,000 premature deaths in England and Wales each year (Cancer Research UK 2009[A]).

Life after cancer

It is known that many cancer therapies are associated with late complications which may impact seriously on the physical, psychological and/or social life of a survivor (Doyle and Kelly 2005, Houldin et al 2006, Richards et al 2011), particularly as the majority of 'survivors' are over sixty-five and often have additional co-morbidities and functional decline (Snydor et al 2009). Arguably, growing recognition of these issues and increasing cancer survival has led to a 'shifting paradigm of cancer care' (Haylock 2006) in which 'survivors' are being acknowledged and their needs addressed within policy. For example, in January 2010, The National Cancer Survivorship Initiative (NCSI) was established in the UK, under the auspices of the Department of Health, Macmillan Cancer Support and other stakeholders (Richards et al 2011). However, disparities in research and care provision across cancer types and patient populations are very apparent. In the UK, research into breast cancer accounted for 20% of site-specific research funding in 2010, whereas the combined spend on stomach, oesophagus, pancreas, brain and lung cancers (which have some of the lowest median survival times) was only 13% (National Cancer Research

Institute 2011). Similar inconsistencies have been observed in the United States (Aziz 2002). It has also been argued that much research into cancer survival reinforces the biomedical model of illness by studying survival in a fragmented way and removing subjectivity (Nettleton 1995) and drawing too heavily from questionnaire based quality of life research (Doyle and Kelly 2005). Rasmussen and Elverdam (2007) argue that this loses sight of the *process* of survival. Breaden (1997) and Thomas-Maclean (2005) suggests that 'needs' are universally defined without consideration of the social context, cultural background, support and/or interactions of those diagnosed with cancer or other illnesses. For example, Breadon (1997) describes how 'cancer survivors' suffer the same nightmares and vulnerability as survivors of catastrophic events, such as earthquakes or fires, but with the additional burdens of fear of recurrence, physical compromise and isolation. The sociological literature on adjusting to life after illness is more highly developed in investigations of other chronic illnesses, for example Bury's (1982) concept of 'biographical disruption' in rheumatoid arthritis.

The concept of 'cancer survivorship'

In the days when cancer was considered incurable, the term 'cancer survivor' defined one who survived the loss of a family member to cancer but, as a reasonable length and quality of life after cancer treatment has become more of a reality, the term has shifted to the person diagnosed with cancer (Leigh 1996, Doll et al 2012). The concept of 'survivorship' was first described by Mullan (1985), a doctor diagnosed with cancer himself. He did not consider that the term 'cure' fully captured the experience of living beyond a cancer diagnosis and described a first, acute phase of cancer survival during diagnosis and treatment, a second, extended phase during remission and a third phase, which he suggested was a permanent phase of 'cure'. Mullan (1985) described survivorship as an independent phenomenon, with survivors having unique concerns and experiences as they

moved towards the permanent survival phase. The terms 'cancer survivor' and 'cancer survivorship' were then adopted and endorsed by organisations keen to empower those who had previously had passive labels, such as 'cancer patients' or 'cancer victims', and to direct services and research towards the post-treatment phases (Park et al 2009, Khan et al 2011[A]).

Large organisations such the NCSI in the UK and the National Cancer Institute in the USA now define cancer survivorship broadly as the time from the point of a cancer diagnosis until death (Khan 2011[A], Doll et al 2012). However, the definition is inconsistent and debate continues about when survivorship should start (anytime from diagnosis to a recurrence-free period of five years or more) or end (end of remission, end of treatment or end of life) (Aziz 2002, Aziz and Rowland 2003, Doyle and Kelly 2005, Lewis 2006, Haylock 2006, Doll 2012). There has also been a recent backlash from those living with the disease who do not necessarily identify with the term and there has been concern raised about what started as a descriptive term now being assumed to be biologically precise (Twombly 2004, Khan et al 2011[A]).

The cultural representation of cancer in contemporary society

Culture was first explicitly defined by the nineteenth century British anthropologist, Edward Tylor as:

> That complex whole which includes knowledge, belief, art, morals, law, customs and any other capabilities and habits acquired by man [sic] as a member of society.
>
> (Edward Tylor 1871 cited in Baldwin et al 1999, p6).

As such, culture defines how a society perceives their world and influences beliefs, behaviours and attitudes, including the way that health and illness are recognised (Helman

2000). It is through cultural representation and practices that information is communicated (Hall 1997, Baldwin et al 1999, Rose 2007) and, as Fitzpatrick stresses, "culture ... enters into the very nature of illness" (Fitzpatrick 1989, p256). Furthermore, cancer has been described as a 'cultural phenomenon' which is imbued with special and significant imagery and meaning in our society and one that is often depicted within art and the media (Sontag 1991, Stacey 1997). There are many cancer descriptions in art, literature and poetry and, recently, autobiographical illness narratives or 'autopathographies' have become increasingly common (Aronson 2000, Sakalys 2000, Thomas MacLean 2004). Well known examples include those of the journalists John Diamond who wrote about his experience of head and neck cancer and Ruth Picardie who wrote about her breast cancer (Picardie 1998, Diamond 1999). Cancer is often depicted on film and television and is highly visible in the new media (Lupton and Chapman 1994, Entwhistle 1995, Clark 2004, Fernández-Morales 2009). It is evident in the increasing number of cancer-related articles that have appeared in women's magazines throughout the twentieth century (Black 1995, Bunton 1997, Andsager et al 2000) and the more recent appearance of cancer as a topic in men's magazines (Clarke 1999, Clarke and Robinson 1999, Bunton and Crawshaw 2002).

However, cultural representations are never neutral and are constructed through various practices, technologies and ways of knowing (Baldwin et al 1999, Rose 2007). All accounts are created within the dominant paradigms of a specific society and it is important to examine their structure and political role before accepting them as 'true' representations of a disease experience (Thomas MacLean 2004, Sakalys 2000). For instance, the Glasgow Media Group has explored the effect of media images on users of mental health services and their families and friends and found that the majority of media representations of mental health problems relate to violence, which has a major damaging and stigmatising effect on these people (Philo 1996). In her early, influential work, Sontag (1991) identified

dramatic, militaristic metaphors such as "fight" and "crusade" (Sontag 1991, p59) that are used to describe cancer and argued that these may infer that people with cancer are culpable for their illness and responsible for its outcome. Since her analysis, social scientists have given attention to cancer-related media reporting. For example, Seale (2001[A]) notes the predominance of what he refers to as 'struggle' metaphors used in English language news stories about people with cancer. He also argues that people with cancer are often portrayed as being engaged with issues of morality and responsibility, which have traditionally been religious themes (Seale 2001[B]). Lupton identifies a military perspective in Australian news reports about breast cancer and argues that disease and death are seen as the enemy "with the patient as the passive battlefield upon which the war is waged" (Lupton 1994[B], p84). She argues that this displaces the patient as secondary to medical procedures and constitutes a technical imperative in media reporting. She also identifies concepts of femininity and responsibility dominating news coverage and argues that this ascribes blame to women with breast cancer. For example, women are reported as being able to protect themselves by staying slim, avoiding becoming 'career women', having children before the age of thirty and examining their breasts regularly.

Stacey (1997), writing about her own experience of cancer and the way cancer is perceived and made sense of within contemporary society, argues that cancer is constructed as a physical symptom of many problems in contemporary society, such as pollution and crime. She claims that contemporary Western culture encourages a belief in success and progression in which loss and failure are permitted but only within a broader picture of ascendancy and suggests that cancer survival stories reproduced, for example, in the media clearly represent this image of disorder becoming order. She says, "it is impossible to have cancer and not be seduced by the power of such cultural narratives" (Stacey 1997, p13). I

would add that it is also probably impossible *not* to be seduced by these cultural narratives, whether one has cancer or not.

Rationale for the thesis

The impact on life and how to live with cancer was the key theme identified by people affected by cancer from the Macmillan Listening Study (Corner et al 2007) and an identification of the needs of 'survivors', particularly the psychological and social impact of cancer, is a stated priority of the NCSI (Richards et al 2011, Richardson et al 2011). Considering this and taking into account the current phenomenon of increasing but disparate cancer survivorship and my interest in the cultural representation of cancer, the rationale behind my work is to seek a better understanding of the impact on life and living with cancer and to investigate the needs of 'survivors' but to do so by addressing some of the areas of research identified as 'missing' (Richards et al 2011, Richardson et al 2011) and explore what it means to be a 'cancer survivor' from the perspective of people diagnosed with less well researched and less 'survivable' cancers.

Research aim

The aim of this research is to explore the experience of living with and beyond cancer from the perspective of people diagnosed with a 'poor prognostic' cancer and contextualised within the social and cultural representation of cancer in contemporary UK society. The work is informed by relevant literature and draws on my principal study in which thirty people who had completed cancer treatment described the impact of the disease on their lives verbally and visually.

Research questions

While focusing on the broad question of:

What is it like to live with and beyond a diagnosis of an expected poor-prognostic cancer in a society that celebrates survival?

I will also address the following questions:

- What are the main concerns and challenges faced by people living with and beyond a poor prognostic cancer?

- Does the experience of living with and beyond a cancer diagnosis correspond to any existing theoretical models?

- Is photo-interviewing an appropriate and useful method for gathering data about living with and beyond cancer?

Theoretical perspective and research strategy

Symbolic interactionism

I am approaching the work from a symbolic interactionist perspective focussing on the meaning of cancer for those living with it. Symbolic interactionism is one of the major theoretical perspectives in sociology and is grounded primarily in the work of theorists such as George Herbert Mead (Mead 1934) and Charles Horton Cooley (Cooley 1902), who, reacting against earlier emphases on biologically determined patterns of behaviour, sought to pay more attention to consciousness and the social creation of the self (Bilton et al 1987). Although there are a number of versions of interactionist thought, some deriving from phenomenological philosophy, Herbert Blumer, who studied with Mead, is generally credited as formulating the most prominent version of the theory and for coining the phrase 'symbolic interactionism' (Blumer 1969, Tsourvakas 1997).

Symbolic interactionism focuses on the subjective aspects of social life rather than on the more objective and structural aspects of social systems. For symbolic interactionists, humans are not simply driven by learnt behaviour but are pragmatic actors who continually

adjust their behaviour through reflection and come to know who they are and how they should act from their interpretations of other peoples' responses to them. As Mead explains:

The individual is continually adjusting himself [sic] in advance to the situation to which he [sic] belongs and reacting back upon it. The self is not something that exists first and then enters into a relationship with others, but is so to speak, an eddy in the social current and so still a part of the current.

(Mead 1934, p182).

Thus, humans are seen as active, creative participants who construct their social world rather than compliant and conforming objects of socialization (Mead 1934, Tsourvakas 1997). Cooley (1902) describes what he calls the 'looking glass self' in which sense of self is created in a threefold process by the reactions of others; firstly the individual imagines how he or she appears to others, then imagines others' judgements based on this and finally develops an emotional and self-conscious response to that judgement (Cooley 1902, Robinson 2007). In his own words, the looking glass self consists of:

The imagination of our appearance to the other person, the imagination of his [sic] judgement of that appearance and some sort of self self-feeling, such as pride or mortification.

(Cooley 1902, p184).

These emphases on negotiated reality and the social construction of society also lead to an interest in the roles people play. Erving Goffman, a prominent symbolic interactionist, discusses roles dramaturgically and, in using an analogy to the theatre, argues that human social behaviour is a more or less scripted performance with humans as actors. By adopting

roles and 'performing' in them, individuals strive to convey an identity consistent with the audience and situation, or 'stage', which frames the interaction (Goffman 1959, Robinson 2007).

Symbolic interactionism has been cited as a particularly effective theoretical perspective for guiding conceptually clear and thorough research with the aim of increasing understanding of health and illness behaviour (Bowling 1997, Benzies and Allan 2001).

Theoretical framework

The work is informed by a theoretical framework involving:

- the cultural construction and representation of cancer and ill health (e.g. Stacey 1997, Sontag 1991)
- lay knowledge of cancer and illness (e.g. Blaxter 1983, Helman 2000)
- adjustment to ill health and biographically informed perspectives of chronic illness (e.g. Bury 1982, Charmaz 1983)
- 'cancer survivorship' and identity.

Photo-interviewing

Appropriate research methods for symbolic interactionism focus on observable face-to-face interactions rather than macro-level structural relationships involving social institutions. As such, symbolic interactionists argue that close contact and immersion in the everyday lives of participants is necessary for understanding the meaning of actions, the

definition of the situation itself and the process by which participants construct the situation through their interaction (Bilton et al 1987).

Observing this and with an epistemological commitment to participatory research and research methods that provide equity (as far as is possible) in the distribution of knowledge and power between the researcher and research participants. I have incorporated a photo-interviewing method (adapted 'photovoice') which uses interviews in combination with participant-produced photographs to express knowledge and illustrate experience (Wang and Burris 1997, Wang et al 1998, Baker and Wang 2006). Furthermore, this method is not entirely dependent on narrative as I am aware that people with cancer may have physical or emotional communication problems. Visual methods and the particular photo-interviewing technique I have used are explored fully in chapter four.

Terminology

In 2008, the charity Macmillan Cancer Support and the NHS Cancer Services Collaborative 'Improvement Programme' held a workshop for people affected by cancer to ensure their views fed into the NCSI. The attendees agreed that the definition of a 'cancer survivor' should be someone who:

- has completed initial cancer therapy and has no evidence of disease *or*
- is living with progressive disease but is not in the terminal phase of illness *or*
- has had cancer in the past.

Attendees were also asked which term they felt was most helpful in describing the period of cancer survival. They voted for the term 'living with and beyond cancer' rather than 'survivorship' and other similar descriptors. I have adopted their definition of a cancer

survivor for my work and intend to use their preferred term of 'living with and beyond cancer' wherever possible throughout my work.

Writing style and reproduction of photographs

I have chosen to write my thesis in the first person as this is a personal and reflexive piece of work in which I accept that I am integral to the research process and I wish to retain some proximity with the reader (Creswell 1994, Sandelowski 1998, Horsburgh 2003, Aveyard 2010). Participants' narrative extracts have been reproduced verbatim although pronunciation has been included to make them more legible. These and photographs are identified by the individual participant's study number and the interview to which they allude i.e. 16.2 is a quote from participant 16's second interview. All photographs have been reproduced within the thesis as they were given to me and without any editing by myself. Although the participants generously gave permission for me to reproduce all but two of the total 249 photographs, I have chosen not to include some if, for example, there are other identifiable people in the photographs (for whom consent cannot be confirmed) or the photographs show names and addresses. Some participants have foregone their complete anonymity so that they can copyright their photographs. In these cases copyrighted photographs are labelled with the participant's first initial and family name.

Chapter guide

Following this introductory chapter in which I have presented some of the features that are known about the experience of living with and beyond a cancer diagnosis today and which form the basis of my thesis and allow a justification for my research rationale, I will present a theoretically-driven chapter (chapter two) that will discuss narrative as a way of articulating ill health and the biographical impact of a diagnosis. I will then examine whether the current models available are applicable to a cancer diagnosis. In chapter three,

I will describe a systematic literature review I performed about the contemporary lay understanding of cancer which offers an insight into the societal perception of cancer. I will then explain the methodological framework that I have adopted for the empirical study, why this seemed appropriate and the necessary considerations that this methodology and associated methods raises in chapter four. Chapter five describes the method and processes of my feasibility study and chapter six discusses the results. In chapter seven, I explain the method and processes I used to conduct my principal study. I then describe and discuss my results in chapter eight. In chapter nine I discuss the key findings and propose some recommendations that have evolved from the research. In chapter ten I reflect on the method and research process for both myself and the study participants. Finally, in the concluding chapter (chapter eleven), I present a conclusion to the full thesis.

Chapter 2

Cancer: biography and narrative

Introduction

Changing demographic patterns have led to "the 'greying' of the Western population" (Williams and Bendelow 1998, p16) and a consequent increased prevalence in chronic illness and disability. Often disruptive, difficult to manage and sometimes leading to a lifetime of discomfort and uncertainty, a diagnosis of a chronic illness may initiate a search for meaning in the sufferer (Bury and Gabe 2004). Sociologists have attempted to explore this 'meaning', either by detailing the consequences of chronic illness or by investigating its wider cultural significance (Bury 1991, Williams and Busby 2000). In this chapter, I will discuss two areas of work that have contributed significantly to this; one being how people use narrative to give meaning to their experience and describe it to others and the other being the impact of chronic illness on the identities and biographies of individuals (Lawton 2003).

Narratives of illness

Narratives, understood as "accounts of what happened to particular people – and what it was like for them to experience what happened" (Herman 2007, p3) and involving sequential chains of interconnected events or actions (Carlick and Biley 2004, Gabriel 2004), offer a way of giving meaning to processes and change which may contrast with, but are not inferior to, more 'scientific' explanations. Although important in all aspects of life, narratives appear to have particular relevance in the re-establishment of meaning that has been threatened, such as when illness occurs (Kleinman 1988, Hydén 1997, Bury 2001, Gabriel 2004, Drew 2005) and a particular strength when examined under a symbolic interactionist framework (Kelly and Field 1996). As Bury states, "under conditions of

adversity, individuals often feel a pressing need to re-examine and re-fashion their personal narratives in an attempt to maintain a sense of identity" (Bury 2001, p264). As such, illness narratives articulate the individual's perception of their place in the world as well as the causes and consequences of a physical or mental condition (Blaxter 2010). Frank suggests that, "becoming seriously ill is a call for stories" (Frank 1995, p53), both in the literal sense of an individual having to explain it and its impact in an understandable way to his or her many different acquaintances, such as clinicians, employers, colleagues, family and friends, but also as a means of making the illness and its cause comprehensible to the individual and re-orientating the self during its presence (Williams 1984, Frank 1995). As such, 'illness narratives' allow a personal, holistic interpretation which is outside, and may be at odds with, the dominant biomedical explanation (Clark and Mishler 1992, Hydén 1997). According to Hydén (1997) illness narratives may be oral or textual, collective or individual and, although 'belonging' to the ill person (Kleinman 1988), may also be reconstructed and represented by other significant people, such as family members, friends or clinicians.

As Bury (2001) explains, before the mid-19th century a doctor's ability to take a history from a patient was vital. He explains that illness was not considered to be disconnected from everyday life and the patient's history would have included information about their lifestyle, moral perspective and physical and social environment. From this narrative, the physician would have been expected to develop treatment procedures, usually with the intention of restoring the patient's and their body's 'equilibrium'. However, Bury (2001) argues that the rise of the scientific paradigm and development of the 'biomedical' model of illness, with its reductionist emphasis on objective signs and symptoms and assumption that the body is a machine in which the repair of a malfunctioning part will 'treat' the problem and the subsequent expansion of medical and surgical procedures, led to the emergence of a privileged and powerful medical profession which had almost complete

jurisdiction over illness and treatment. This had the effect of making people passive in the face of their own ill health, silencing their accounts of suffering and making subjective explanations virtually irrelevant (Bowling 1997, Bury 2001). As Morris explains, patients became "the more or less unreliable narrators of their own unruly illnesses" (Morris 1998, p38). However, narratives of illness or, more precisely, narratives of "a life disrupted by illness" (Garro and Mattingly 2000, p27), have been brought back under the spotlight recently due to changes in the way illness is experienced, i.e. from acute diseases which can be treated and hopefully cured to more chronic illnesses which demand management and care (Frank 1995, Small and Rhodes 2000, Bury 2001, Blaxter 2010). The emphasis on management and care is also supported by the postmodern approach which respects the plurality of knowledge and diversity of experience. This allows for a more holistic and 'patient focused' relationship to come to the fore in some (if not all) areas of medicine (Clark and Mishler 1992, Morris 1998, Williams and Busby 2000, Bury 2001). It is argued that these, together with the erosion of hierarchy and increased access to information in society generally, have encouraged a greater awareness and promoted the development of illness narratives (Bury 2001, Blaxter 2010).

Narrative is one of the most fundamental ways in which we comprehend experience, judge our actions and apply meaning and value to our lives (Hydén 1997, Garro and Mattingly 2000, Charmaz 2002). Frank describes serious illness as being the "loss of the destination and map that had previously guided the ill person's life" (Frank 1995, p1). This potentially challenges all previous knowledge about the integrity of the body (Becker 1997) and, as such, "illnesses become narratives very rapidly" (Stacey 1995, p5). In describing her own response to a diagnosis of teratoma, she explains:

> Some sense is sought of time and sequence, sense for others and for oneself. The
>
> past confusion is explained; the present situation requires a story (I struggle to

offer a coherent answer to the question, 'What has happened?'); and the future

presents the possibility of terrifying resolutions (What are my chances of survival?).

Only a little information is necessary and the narrative structuring begins: linearity,

cause and effect and possible closures present themselves almost automatically.

Stacey 1995, p5.

Her experience is mirrored by many others who have published 'cancer narratives' in recent years (for example, Picardie in 1998 and Diamond in 1999). Illness narratives can therefore assist the 'sense-making' she describes and create an important forum in which an individual's identity can be amended and integrity reinstated (Kleinman 1988, Mathieson and Stam 1995, Bury 2001, Carlick and Biley 2004). Williams has called this 'narrative reconstruction' and describes it as an attempt to "repair ruptures between body, self and world" (Williams 1984, p197).

The limitations of illness narratives

The interpretation of illness narratives is not always unproblematic. They can have many diverse functions, for example in constructing a new identity or social world, recreating a previous life story or strategically explaining or make use of illness (Kelly and Field 1996, Blaxter 2010). Creating or listening to a narrative is both dynamic and productive and draws on personal, cultural and social knowledge (Garro and Mattingly 2000, Small and Rhodes 2000). Narratives comprise both the individual's presentation and the audience's interaction (Mathieson and Stam 1995). Usually, individuals are implicitly aware of the socially approved way in which they *should* talk about their experiences (Drew 2005). As such, an illness narrative may differ depending on who it is delivered to, when and under which social conditions, with 'public' descriptions offering 'approved' accounts and 'private' explanations often being less moralistic and more pragmatic. It is therefore

necessary to understand both the stories told by individuals about their experience and the cultural shaping of those stories (Radley and Billig 1996, Small and Rhodes 2000, Morris 2000, Bury 2001, Charmaz 2002, Drew 2005). Furthermore, narratives are ambiguous because they lack a conclusion. As Blaxter (2010) says they need to be continually renegotiated and there is always the possibility of a different 'ending'.

Biographical Disruption

The "loss of the destination and map" (Frank 1995, p1) previously described as being inherent when a serious illness is diagnosed has also been termed 'biographical disruption' (Bury 1982, Garro and Mattingley 2000, Small and Rhodes 2000, Lawton 2003). Biographical disruption was first described by Michael Bury who recognised it in the narratives of people he was interviewing in England with newly diagnosed rheumatoid arthritis (RA), a chronic, progressive, painful and debilitating auto-immune disease affecting the joints (Bury 1982, Panayi 2011). Bury draws on the work by Giddens (1979) who claims that 'critical situations', such as war, can undermine taken for granted assumptions about society and argues that the diagnosis of an illness, in particular a chronic illness such as RA, is similarly critical and has the potential to threaten an individual's identity and relationships and throw the future into question. He says:

> Chronic illness involves a recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities. In addition, it brings individuals, their families, and wider social networks face to face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support ... Further, the expectations and plans that individuals hold for the future have to be re-examined.

> Bury 1982, p169.

Bury lists three features of the disruption caused by a chronic illness. These are the onset of the illness and the problem of recognising what it is, emerging disability and uncertainty and the mobilisation of resources to manage a chronic illness. These are described below:

Onset and recognition

Chronic illness often has an insidious onset and Bury's participants had not recognised their early symptoms as being of RA. However the start of such an illness brings what are usually unproblematic and ignored bodily states into consciousness (Bury 1982, Williams and Bendelow 1998) leading to what Williams calls a "'what is going on here?' stage" (Williams 2000, p43). As symptoms persisted and the possibility of an arthritic illness became more inevitable, Bury's participants were often left in shock because their stereotypical view of arthritis as a disabling disease of the elderly was at odds with their own self identities. As he says, "commonsense assumptions lose their grip and yet alternative explanations do not readily present themselves" and he labels this as a "biographical shift" from a perceived 'normal' life trajectory to one that is aberrant and damaging (Bury 1982, p171). In line with Zola's (1989) early work on 'becoming a patient', the respondents were unsure who, what and how to tell and referral to specialist services was often protracted. However, diagnosis often came with relief and high expectations as symptoms were then legitimized and could be 'sorted out.'

Emerging disability and uncertainty

This phase was marked by "the uneasy balance which is struck between seeing the condition as an outside force and yet feeling its invasion of all aspects of life" (Bury 1982, p173) or, as Kelly and Field (1996) describe, being the same person but in a different social situation. Doctors were important now as they could prescribe drugs to relieve pain and discomfort but they could not necessarily provide explanations and reasons. So, as has

been noted in other studies of lay explanations for the causes of illness (e.g. Pill and Stott 1982 and Blaxter 1983), individuals fell back on their own "biographical experience" (Bury 1982, p174) to find reasons for the onset of their RA, which were often based on theories of inheritance or emotional shock. Furthermore, the respondents came to realise that both medical knowledge and treatments were limited and the most pressing and difficult task was going to be learning how to live with it.

The mobilisation of resources

The final feature of biographical disruption concerns the maintenance of 'normal' activities and relationships in the face of a new illness. As Bury describes, "The erstwhile taken-for-granted world of everyday life becomes a burden of conscious and deliberate action" (Bury 1982, p176). Previously straightforward social activities began to demand strategic planning and additional time. As such, some of Bury's respondents were forced or chose to restrict them entirely or limit them to only the very familiar. This in itself caused social isolation for many and was exacerbated by those who were trying to maintain paid work. Even the most sympathetic managers and colleagues reached the limits of tolerance when they had to consistently work longer or harder to cover frequent absences or participants' inability to do certain tasks. As Becker (1997) describes, maintaining a sense of normality in the face of illness requires much more than the physical ability to take part in activities. However, depending on what is fundamental to someone's identity, the restrictions caused by illness may make the maintenance of any kind of normality impossible, leading to a life devoid of meaning.

Bury also distinguishes between what he calls "meaning as consequence" and "meaning as significance" (Bury 1988, p91). Meaning as consequence denotes the meaning of chronic illness created by any physical restrictions and resulting social disadvantages for the

individual, whereas meaning as significance represents the connotations and imagery that the illness itself carries which may have a profound effect on the way individuals both see themselves and perceive others see them (Bury 1988, Bury 1991, Sanders et al 2002).

Publishing at about the same time, Charmaz (1983) came to a similar view from her research with people diagnosed in America with a variety of chronic illnesses that caused them to be severely physically debilitated. She labelled the disruption caused by illness "loss of self" and described it as "a crumbling away of their former self-images without simultaneous development of equally valued new ones" (Charmaz 1983, p168). Like Bury, she explained the reciprocal and spiralling consequences of serious chronic illness such as loss of role, financial difficulties, strain on relationships and stigma, as well as a restricted life. For her respondents, illness experience was complex and aspects often reinforced and amplified each other in negative ways. For example, feeling stigmatized caused a loss of self-esteem, which led to a withdrawal from social situations, thus increasing feelings of 'loss of self' because of the inability to maintain self-worth through meaningful interaction with others (Charmaz 1983, Lawton 2003).

Critiques of biographical disruption

In the thirty years since 'negotiation' models, such as 'biographical disruption' and 'loss of self', were first outlined a rich body of sociological work has been produced describing the biographical impact of illness in a wide range of illnesses and diseases (Kelly and Field 1996, Williams 2000, Hughes et al 2009, Reeve et al 2010). As Williams (2000) suggests in his important and comprehensive article on biographical disruption and its contemporary relevance, it has proved to be an enduring and important theory on which to base studies about the meaning of, consequences of and adjustment to chronic illness and allowed the voices of those who are ill and their families to be heard and recognised. However, there

has been some recent debate about its conceptual strengths and weaknesses (Williams 2000, Lawton 2003, Grinyer 2007, Reeve et al 2010). Here I discuss the most common questions raised by the debates:

Is biographical disruption dependent on context and personal expectation?

The context in which an illness is experienced has been a central theme in much of the debate concerning biographical disruption, for example age at diagnosis (Williams 2000, Lawton 2003). Williams (2000) discusses how it is misplaced in any discussion of congenital or early childhood illnesses. As he explains, such illnesses may appear to be profoundly disruptive but it is unlikely that biographies have had to be modified where no prior 'healthy' or 'normal' identity pre-existed. This is supported by a study of children and young people with cystic fibrosis in which a process of continual biographical revision in anticipation of future exacerbation of illness appeared more relevant (Williams et al 2009).

Bury (1982) does not detail his respondents ages but they are described as predominantly young or middle-aged and, RA, typecast for many respondents as a disease of older age, was hugely disruptive. However, researchers who have studied the onset of chronic disease in older populations have found it to be less so. For example, Sanders et al (2002) examined the significance of a diagnosis of osteoarthritis in an older age group (age 51 to 91) and found a co-existence between biographical disruption and an expected life biography. Although the *consequences* of osteoarthritis in their respondents' daily lives had many similarities with Bury's respondents, the connotations and *significance* placed on those symptoms were different. The disruptive impact of symptoms was acknowledged but the implication was that osteoarthritis was a normal part of getting older and the respondents tended to 'play down' their impact in a bid to be seen as independent. Pound et al (1998) studied the impact of a stroke on older (mean age 71), working class Londoners. For this

population, many of whom lived with co-morbidities and had generally lived 'hard-earned lives' (Cornwell 1984), a stroke was less a disruption and more a "normal crisis" to which they were resigned (Pound et al 1998, p497). Of interest, there was a general consensus among their respondents that a stroke would be more disruptive for younger people and the only person who did express anger at what had happened was their youngest respondent. Faircloth et al (2004) found similarities with their population of older men recovering from a stroke in Florida and Puerto Rico and developed "biographical flow" as a more appropriate term to describe how their respondents described the impact of a stroke as part of an on-going, older life (Faircloth et al 2004, p256).

Pound et al (1998) and Faircloth et al (2004) concluded that many of their respondents did not find a stroke to be particularly disruptive partly because many of them had experienced poor health before. This was further reflected in Carricaburu and Pierret's (1995) study of Parisian men who had contracted HIV through gay sex or treatment for haemophilia. All of the men had to re-evaluate their sense of identity but, for those living with haemophilia (and therefore already organising their lives around an illness trajectory and used to living with uncertainty), the diagnosis was more about what Carricaburu and Pierret describe as "biographical disruption that entailed a biographical reinforcement" which therefore proved "the fatality of being haemophiliac" (Carricaburu and Pierret 1995, p81 and 82). The respondents who had been healthy before their diagnosis found it harder to reconcile the disruption to their identity. Ciambrone (2001), in her study of women with HIV from the North East USA also examined the contexts of her participants' biographies. She found that, although disruptive, in the light of lives that had often experienced drug use, prostitution and poverty, a diagnosis of HIV was not necessarily the most disruptive element.

These studies have been used to contest Bury's concept of chronic illness causing biographical disruption by suggesting that certain circumstances, for example older age, co-morbidity or social disadvantages, make chronic illness experience a 'normal crisis', part of 'biographical flow' or even a 'biographical reinforcement' (Williams 2000, Lawton 2003, Sinding and Wiernikowski 2008). Bury's respondents were working class but younger than the populations studied by Sanders et al (2002), Pound et al (1998) and Faircloth et al (2004). The majority worked and had led physically active lives prior to their diagnosis. The experience of receiving a diagnosis of a debilitating chronic illness when an individual is younger, physically active and fulfilling a role (such as being in paid employment or being responsible for young children) or, indeed, encountering a disease that an individual only thought affected others (in this case older people) may have a greater impact on biographical disruption than it does for people who are older or who are more used to disruption in their lives. This warrants more research but three recent studies support this. Soklaridis et al (2011) ran focus groups for people injured at work and living with injury related chronic pain and found that the resultant changes and losses led to considerable biographical disruption. Anderson et al's (2010) study of people who were HIV positive and living in London found that biographical disruption felt at diagnosis was related to their understanding that those at risk were gay or promiscuous and therefore 'not them'. Finally, Wilson (2007) detected significant disruption in the biographies of her Scottish female HIV positive research participants related to their identity as mothers, both from HIV-related stigma and their potential mortality.

Concerns have also been raised about biographical disruption possibly being an artefact of the research process (Bury 1991, Charmaz 2002, Reeve et al 2010) and it may be helpful to consider how people tell their stories in interviews. Bury (1991) suggests that people may 'bracket off' the impact of their illness as a way of coping and maintaining their pre-illness

identity and Cornwall (1984) drew a distinction between 'public' and 'personal' accounts of illness with the former seeking to "affirm and reproduce the moral order" and the latter referring more to bodily experience and pain (Kelly and Field 1996, p261). Arguably the "confessional discourse" (Gabriel 2004, p179) of late modernity, and one which the younger respondents in Soklaridis et al's (2011) and Anderson et al's (2010) studies may have been more likely to use, draws more on Cornwall's personal accounts of illness. As such, the older respondents in the studies by Sanders et al (2002), Pound et al (1998) and Faircloth et al (2004) may be less likely to 'grumble' and more likely to normalise their illness in response to cultural prescriptions about how they think illness should appropriately be managed and discussed (Sinding and Wiernikowski 2008).

Can biographical disruption be a cause of illness?

Less a critique and more of a complement to the concept of biographical disruption, Williams (2000) argues that it has been implicitly presented as a cause of ill health in some illness narrative studies. For example, Williams (1984) presents three case studies which explore the lay attribution of the causes of RA. One of his respondents justified her illness by, what she described as, her close relationship with a god who also suffered but the other two laid the blame squarely at disruptive events, namely having to work in a contaminated environment and negotiating the stress caused by a rapid succession of difficult and relationship damaging life events. More recently, Lawton et al (2007) have explored the reasons given for the cause of their diabetes by white and South Asian people living in Scotland. Although their white respondents tended to emphasise the role of their own lifestyle 'choices', the South Asian respondents were more likely to blame disruptions in their life story, particularly linked to emigrating to the UK. Such 'mind/body medicine', whereby emotional stimuli are thought to produce physiological changes, have been viewed sceptically by biomedicine although they are central to many forms of

complementary or alternative medicine and are gathering credence in some specialist

areas, such as psychiatry and pain management (Bendelow and Menkes 2006). As such,

Williams (2000) suggests that, theoretically and empirically, biographical disruption might

provide an important aetiological link to the cause of illness and provide a bridge between

the sociology of chronic illness, the sociology of emotions and social models of illness and

disease.

Is the concept of biographical disruption out of date?

Williams (2000) discusses whether biographical disruption has a place in 'late-' or 'high-

modernity'. Modernity typically refers to a post-traditional society and late-modernity to

the presently developed phase of modernity (Giddens 1991). Defining features therefore

include globalisation, consumerism, rapid developments in information technology,

urbanisation and individualism (Webster 1995, Pelikan 2006). Some of the health-related

aspects of late-modernity include the influence of the growing fitness and beauty

industries, the changing parameters of risk and the rise of health promotion, the

commodification and consumption of healthcare and the dilemmas associated with the

development of technology and its impact on mortality (Williams and Bendelow 1998,

Henderson and Petersen 2002, Pelikan 2006, Kellehear 2007).

Giddens, a sociologist who has written extensively on the consequences of late modernity,

describes self-identity as an "ongoing story about the self" (Giddens 1991, p54). He

explains how this has to be developed in the midst of a bewildering range of unknown

possibilities:

> The reflexive project of the self, which consists in the sustaining of coherent, yet
>
> continuously revised, biographical narratives, takes place in the context of multiple
>
> choice as filtered through abstract systems... The more a tradition loses its hold,

and the more daily life is reconstituted in terms of the dialectic interplay of the

local and the global, the more individuals are forced to negotiate lifestyle

choices among a diversity of options.

Giddens 1991, p5.

Kelly and Field (1998) argue that, in this late-modern world of less definite social structures

where concepts of 'normality' are more diverse, the assumption that chronic illness will

unavoidably disrupt in a negative way should be questioned. They do not dispute that

chronic illness may have a profoundly limiting effect for individuals but suggest that new

paradigms will embrace the diversity and change wrought by chronic illness. However, as

Williams contends, this may be an overly optimistic interpretation and a greater plurality

may actually generate its own forms of control, or as he describes, "a new 'inflexible

flexibility'" Williams (2000, p57). Williams and Bendelow (1998) and Williams (2000) draw

on the contemporary enthusiasm with 'holistic health' to argue that, although this may

paint an optimistic picture of individually controlled wellbeing in contrast to biomedicine

and its obsession with cure, its emphasis on personal responsibility may deflect attention

from the wider political economy of health and illness and bring with it its own means of

disempowerment. They also use the example of health promotion and screening, which

they maintain will worsen as the Western population ages and becomes more 'at risk', to

illustrate a growing "surveillance medicine" and control (Williams and Bendelow 1998,

p70). In turn, this inspires feelings of constant vulnerability and anxiety about illnesses that

are unknown or will emerge in the future (Lupton 1994[A]).

Therefore, as Giddens (1991) and Williams (2000) suggest, the increased potential of self-

identity and opportunities for biographical revision that late modernity brings can be both

liberating and constraining. Our bodies can no longer be taken for granted and our

biographies become influenced by, for example, health promotion, emotional work and other imperatives deemed necessary to maintain or own health and wellbeing. Arguably, the responsibilities inherent in "behaving 'healthily'" (Blaxter 2010, p88) may increase the stigmatising effects of chronic illness in a society where individuals are considered accountable for their good health, thus limiting the mobilisation of resources and increasing feelings of biographical disruption for the individual. Furthermore, choice and responsibility coupled with technology and surveillance blurs the boundary between the healthy and the ill (Blaxter 2010). This may create a cohort of 'worried well' living with biographical disruption. This has been highlighted by Kenen et al (2003[A and B]) who detected issues related to biographical disruption in their sample of healthy women living with a family history of breast or ovarian cancer.

As Williams (2000) argues, the study of biographical disruption needs to be extended to encompass:

- A more detailed focus on the full life-course, including the relevance of biographical disruption of childhood illnesses and illnesses of old age

- A greater attention to the context and circumstances that 'problematise' or 'normalise' illness

- An analysis of the role of biographical disruption itself in the genesis of chronic illness

- Further work on the health related implications of social reflexivity associated with late modernity.

However, I would argue that biographical disruption remains a relevant and promising theory, even if it needs to be finely-tuned from the one first envisaged by Bury thirty years ago. As Williams considers, it appears to offer a meaningful premise on which to base

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theories concerning the impact of and adjustment to the diagnosis of a chronic illness and remains "a 'continuous' theme in a 'changeable' world" with "a 'healthy future'" (Williams 2000, p55).

Biographical disruption and cancer

Studies of illness experience have been overwhelmingly concerned with chronic illness (Lawton 2003). When biographical disruption was first described, cancer was more often seen as an acute disease with a predictable and usually fatal trajectory (Corner 2008, Hubbard et al 2010). As such, there is little reference to cancer in early published work on the relevance of biographical disruption (Leveälahti et al 2007). However, the past decade has seen a growing body of work investigating biography and cancer. This poses two questions; firstly, has the nature of cancer changed so that it is generally experienced as a chronic illness now and, if so, does living with cancer invoke biographical disruption?

Is cancer experienced as a chronic illness?

A study presented at this year's American Association For Cancer Research Conference (Ning 2012) found that half of people diagnosed with cancer die of other causes. Recent improvements in treatment and supportive care have increased cancer survival overall and are allowing individuals to live with it for many years. As such, cancer is often being categorised less as a potentially life threatening disease and more as a long term or even chronic illness (Foster and Fenlon 2011, Richards et al 2011). However, it has been argued that cancer may be dissimilar from many of the 'traditional' chronic illnesses, such as heart failure, diabetes or arthritis. For example, Tritter and Calnan (2002) explain that cancer is distinctive because it encompasses a huge range of different diseases with markedly diverse incidence, treatments and outcome whereas most other chronic illnesses are more clearly defined and life-long. Unlike many chronic illnesses which are characterised by

increasing dependency and contact with healthcare systems, cancer is distinctive because it prompts a very urgent and multidisciplinary response at diagnosis. Acute illness and intense periods of treatment are then interspersed with 'follow-up' phases, which may include remission, sub-clinical progression or managed supportive care and treatment. Although these phases may appear more akin to chronic illness, they are usually defined by disease surveillance rather than the support and rehabilitation more generally offered to chronic illness sufferers (Tritter and Calnan 2002, Corner 2008). Tritter and Calnan (2002) also differentiate cancer because of its prominent media profile and cultural perception as a highly stigmatized and fatal illness, as explored by authors such as Sontag (1991), Stacey (1997) and Seale (2001[A], 2002). They suggest that this may enhance any social isolation experienced by people living with cancer. They conclude by arguing that the classification of cancer as a chronic illness may do a disservice to those diagnosed with it as it prevents the consideration of the more acute aspects of the disease or individuals' responses to these. Researchers exploring the experience of *specific* cancers have highlighted other characteristics distinctive of certain types of cancer. For example, Leveälahti et al (2007) argue that lung cancer is not a chronic illness due to its expected short survival whereas Harrow and colleagues suggest that breast cancer is because it "remains with the person" (Harrow et al 2008, p354).

Frank (1995, p8) uses the term "remission society" to describe people living with cancer, chronic illness, disabilities and other 'monitored' states, such as people recovering from addictions. He explains that although the technological advancements of modern medicine have created this society, what it means to live in the wake of illness, where "the foreground and background of sickness and health constantly shade into each other" (Frank 1995, p9) is postmodern. Sontag had previously described how everybody has citizenship "in the kingdom of the well and in the kingdom of the sick" (Sontag 1991, p3) at

some time or other but Frank (1995) describes those living in the remission society as being on permanent 'visa status' between the two. Although modern medicine is granting this status to more and more people, he argues that it has not provided a story or directions and so such people have to take responsibility alone for what illness means in their life.

The overall intention of my thesis is to explore the experience of people living with cancer and is focused on the less acute time after initial treatment. I also focus on those with poorer prognostic cancer types in which a cure is less likely. Therefore, I recognise the more chronic and ever-present characteristics of cancer and find the concept of the 'remission society' that such people may inhabit a helpful consideration. As such, it seems pertinent to investigate the application of the sociological work around chronic disease in this particular case. However, I am aware that features such as constant surveillance, fear of recurrence and further treatment, the ever present spectre of death and the cultural significance of the disease (which may be less significant characteristics of more traditionally classified chronic illnesses) must be considered when examining the meaning of a cancer diagnosis and the adjustment to a life with it.

Does living with cancer invoke biographical disruption?

There is much evidence to suggest that many people who are living with and beyond cancer have physiological, psychological and social effects that they attribute to their cancer diagnosis (Corner 2008, Armes et al 2009, Foster et al 2009, Hubbard and Forbat 2011). However, these tend to employ the prevailing oncological framework which suggests that psychological adjustment is necessary to prevent, for example, anxiety and depression and ignores factors such as the process of recovery, ongoing effects of treatment and fear of recurrence (Corner 2008). Mathieson and Stam (1995) discuss how normative research on the 'problems' of cancer essentially pathologises the person living

with and adjusting to it. They point to the dearth of studies exploring the meaning of the changes as a central theme and call for a focus on the adjustment of identity to reframe psychological and social issues concerning cancer.

Despite these criticisms, there are some recent studies which have employed narrative methods to explore the biographically disruptive elements of responding to or living with a cancer diagnosis and have found similarities to the disruption caused by other chronic illnesses. Most, so far, have studied the initial diagnosis and treatment phase. For example, Cayless et al (2009) and Hubbard et al (2010) have researched the first year after a diagnosis of prostate and colorectal cancer respectively. These two populations came from one cohort of British patients who were interviewed at diagnosis, during treatment and in early follow-up. Interviews therefore captured the phases of urgent and multidisciplinary response, acute illness and intense periods of treatment as described by Tritter and Calnan (2002). Both studies identified threats to identity, such as adjusting to a changed body image and sexuality brought about by treatment side effects and an awareness of mortality, which disrupted biographies. It is not clear from the articles whether Hubbard et al (2010) interviewed more people of working age but they also recognised that a loss of paid work and independence in maintaining housework threatened the identity of some of their respondents with colorectal cancer and were seen as a significant disruption. Hubbard et al (2010) reported two respondents who had former cancer experiences and perceived themselves to have lived a 'hard life'. In keeping with formally discussed studies of people who had encountered ill health and other negative life events (Pound et al 1998, Ciambrone 2001, Sanders et al 2002, Faircloth et al 2004), these respondents reported cancer as disruptive but as more inevitable and not necessarily a threat to identity as in Bury's (1982) original description of biographical disruption. That is, for them, a cancer diagnosis was more part of 'biographical flow' (Faircloth et al 2004) or 'biographical

continuity' (Sanders et al 2002). This was identified in two further studies that explored the initial period following a cancer diagnosis in people who had arguably led long or 'hard lives'. Leveälahti et al (2007) interviewed Swedish men and women at about one year after a lung cancer diagnosis. Although co-mordity was not formally reported, many of their respondents talked about pre-existing illness and other negative life events in the extracts of their narratives reproduced in the article. Sinding and Wiernikowski (2008) interviewed Canadian women in their seventies and eighties with breast or gynaecological cancer, most being within one year of diagnosis. Again pre-existing health concerns were often reported, together with material hardship and other aspects of 'hard-earned lives'. Although some respondents in the two studies reported disruptive elements which involved reassessment of previous held assumptions of lifestyle and expectations and renegotiation of the 'normal' rules of reciprocal support, these were seen as relatively short-lived and the majority were able to incorporate it into their ongoing lives as a "normal hardship" (Sinding and Wiernikowski 2008, p391).

All four of these studies note that some respondents 'bracketed off' their cancer in order to facilitate coping (Bury 1991), often describing it as a short interruption from which life would soon return to normal (Leveälahti et al 2007, Cayless et al 2009, Hubbard et al 2010) or something that should not be thought about, worried about or dwelt upon (Sinding and Wiernikowski 2008). Sinding and Wiernikowski (2008, p402) label this "disruption foreclosed" and suggest that it may mean biographical disruption is present but unidentified in these populations.

The bulk of research on living with and beyond cancer focuses almost entirely on the earliest phases of survivorship and people who have lived longer after a cancer diagnosis have been much less frequently studied (Richardson et al 2011). The few exceptions

include Grinyer (2007) who gathered data via interviews and written narratives from British teenagers and young adults with a cancer diagnosis. Although it is not clear how long her respondents had lived with it, the narratives reproduced in the article were given between one and five years after diagnosis. She found significant biographical disruption, in particular related to body image, sexuality and fertility, plans that had to be relinquished or postponed and a loss of independence, both physically and financially (and at a time when friends were often 'moving on' or 'moving away' from their families). Although not specifically referring to biographical disruption, Drew (2003) explored the personal accounts of young Australians at least five years after a diagnosis of cancer in childhood or adolescence and identified similar themes. A recently published study by Hubbard and Forbat (2011) investigated written accounts of Scottish people who had been diagnosed with cancer for at least a year. Again, they found cancer to be an ongoing physical, psychological and social disruption for their participants, threatening an anticipated life expectancy, course and identity. They also examined characteristics such as participants' ages, time since diagnoses and whether they considered themselves to be 'free' of cancer or not and concluded that the narratives of their respondents, who they called 'cancer survivors', could not easily be categorised as examples of biographical disruption or biographical flow as some of the impacts of cancer were constructed as permanently having a profound impact on anticipated life and identity, whereas other disruptions were downplayed or presented as effectively managed. Importantly, they also identified some examples of disruptions to biography that ultimately had a positive outcome, for example, when the experience of cancer is perceived to be responsible for making respondents 'stronger'.

It is also of note that cancer may cause biographical disruption to those other than the sufferer. An English study by Young et al (2002) on the impact of a diagnosis of childhood

cancer on mothers of the young patients found significant biographical disruption felt in their roles as mothers. Furthermore, these mothers took on the role of "guardians of their child's biography" (Young et al 2002, p1843) and undertook some of Bury's (1982) tasks of meaning-making for their *child's* future biography, for example, seeking a causal explanation. Similarly, a Scottish study explored the ongoing concerns of the male partners of women treated for breast cancer and found elements of biographical disruption in their respondent's reports of changes to their roles and relationships (Harrow et al 2008).

Conclusion

In this chapter, I have presented two areas of work that have been hugely influential in exploring the lived experiences of people who become chronically ill. Namely, how people use narrative to give meaning to that experience and describe it to others and the limitations of this and how the illness may impact on the identities and biographies of individuals, thus causing disruption (Lawton 2003, Drew 2005). I have explained and critically reviewed how biographically informed perspectives of chronic illness, as first described by Michael Bury and Kathy Charmaz, may be used to describe the experience of chronic illness and offer an explanation of the response and adaptation to it (Bury 1982, Charmaz 1983, Hubbard et al 2010). Using examples of more contemporary studies, I have sought to bring the theory up to date and argue that it still has a place in detailing the consequences of chronic illness and investigating its wider cultural significance. I have also explored the disparities between chronic illnesses such as heart failure, diabetes or arthritis and cancer (Tritter and Calnan 2002). I have argued that the growing number of people living with and beyond cancer, particularly a cancer considered as having a poor prognosis, may undergo similar threats to identity and, as such, employing narrative to explore disruptions to biography may be a highly appropriate way to seek a deeper understanding of this relatively recent phenomenon of cancer survival. Finally, a review of the limited

research that has so far taken place in this area has been offered. As this thesis develops,

these will be explored in more detail and specifically in relation to living with and beyond

cancer.

The next chapter will continue this exploration of the contemporary theoretical perception

of cancer by describing a literature review I performed on the lay understanding of cancer.

Chapter 3

Literature Review

What is the lay understanding of 'cancer'?

Introduction

In this chapter, I present a literature review of the contemporary lay understanding of cancer in World Health Organisation (WHO) defined 'high income' countries, such as the UK. Lay concepts of illness causation and the maintenance of health are those created outside the influence of, but not necessarily distinct from, formal healthcare organisations (Armstrong and Murphy 2008). They are highly significant because they dictate how people define themselves and others as healthy or ill, when, why and if they seek professional medical help and how they maintain health (Nettleton 1995). I have chosen to investigate this area because most health care work is performed by lay people, either in self-care or by caring for others (Stacey 1988, Newbould et al 2006), and as both health services and informal care systems move ever more towards the management of long term conditions and disability, including the support of more people living beyond a cancer diagnosis and treatment, an understanding of the lay knowledge shaping this and how it mediates concepts of health and illness becomes highly important to enable effective and appropriate care provision (Popay and Williams 1996).

Background

Studies of the role of lay knowledge of health and illness and its relationship to scientific knowledge or 'expertise' have led to a sociological appreciation that concepts of health and illness are rooted in the concerns, experiences and socio-economic structures of everyday life. They are not simply re-interpreted or 'watered down' versions of medical knowledge but are shaped by an individual's culture, social identity and personal biography (Nettleton

1995, Blaxter 2010, Henderson 2010). Lay knowledge is embedded in the *experience* of illness, rather than the biomedical concept of disease and focuses on the causes, consequences and significance of symptoms and illness on everyday life (Fitzpatrick 1989, Williams and Popay 1994, Nettleton 1995). Herzlich and Pierret (1986) argue that, because illness is often a very significant, difficult and distressing event both for the individual and their social sphere, lay concepts often go beyond the body when trying to interpret cause and meaning and studies have shown that they can be highly complex. For example, Helman's (1986) study, 'Feed A Cold, Starve A Fever' reveals a sophisticated local knowledge of the causes and treatment of colds, chills and fevers. Although such knowledge may sometimes seem at odds with medical science it provides logical and valid explanations to situations or, according to Helman (2000, p91), helps people "make sense" of their illness.

Development of the research question

Lay understanding informs how people talk about their illnesses, define their concerns or distress, evaluate medical interventions and even choose how to cope with them (Dein 2004, Newbould et al 2006, Leventhal et al 1997, Blaxter 2010). Nettleton (1995) describes how an understanding of lay knowledge is crucial to planning effective health promotion which may be undermined if people hold a fatalistic understanding about the cause of a particular illness and Radley and Bell (2007) argue that, as illness is an indicator of an individual's relationships with and within society, it is of prime importance to study its collective interpretation.

It is therefore highly important to recognise what knowledge and beliefs people have about cancer because, whether they are ever diagnosed with it or not, it will influence their entire experience from recognition of symptoms in self or others and presentation to health

services to making sense of illness experienced by themselves or those around them and reacting to it and/or managing it (Buick 1997, Weinman et al 2003). From a symbolic interactionist perspective, it will lead to understanding of the 'roles' people may adopt or be ascribed and their behaviour when defined as 'ill' (Cooley 1902, Goffman 1959). As such, an appreciation of lay knowledge helps to contextualise the notion of cancer held by people and understand where they are 'coming from'. However, discussions about lay beliefs regarding cancer in particular appear to be scarce.

My literature review will therefore seek to answer the question 'What is the lay understanding of cancer?' and will be an attempt to synthesise the literature available and determine what is known about the disease cancer, including understanding of the diversity of diagnoses, treatments, prognoses and outcomes of the many different types of cancer.

Reviewing the literature

There are different approaches to reviewing literature. Aveyard (2010) places these on a continuum with systematic reviews at one end and the more traditional narrative reviews at the other. A systematic review follows a protocol to ensure all relevant literature is identified, critiqued and synthesised appropriately in order to answer a predefined question, whereas a narrative review does not follow any predefined method and is more concerned with gaining an initial impression of the research area (Bryman 2008, Aveyard 2010). There are several limitations of systematic reviews, for example Bryman (2008) suggests that they may lead to a 'bureaucratization' of the review process which then becomes more concerned with the technical aspects of how it is done than with the analytical interpretations generated by it. He also questions the methodological assumptions that inform decisions about research quality and which studies may then be

included or excluded. However, systematic approaches are generally considered the most reliable, comprehensive and unbiased methods of reviewing literature (Bowling 1997, Bryman 2008, Aveyard 2010). For this reason, I have followed a systematic approach known as thematic synthesis for this review (Thomas and Harden 2008) which is described later in this chapter.

Search method

Because lay understanding is rooted in the social and cultural experience of illness, rather than the biomedical concept of disease (Helman 1984, Williams and Popay 2002), I decided that social science databases would be the most useful source of literature to answer my review question. Librarian advice was sought about which would be most reliable and Web of Knowledge, Science Direct, ASSIA, Sociological Abstracts and PsychInfo were recommended. Using Boolean terms and connectors, the following permutations of keywords and terms were searched:

Lay/social/cultural/ public understanding	cancer/oncology/tumour/ tumor/neoplasm
lay/social/cultural knowledge	cancer diagnosis/diagnoses
lay/social/cultural perspective	cancer treatment(s)
lay/social/cultural beliefs	cancer prognosis/prognoses
lay/social/cultural attitudes	cancer outcome(s)

I also searched the references of retrieved articles to augment the review and performed a hand search of particularly relevant journals, i.e. Social Science and Medicine, Sociology of Health and Illness and Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine. In addition I searched the websites of large cancer charities (e.g. Macmillan Cancer Support and Cancer Research UK) and organisations (Department of Health, UK and National Institute of Health, USA) in the hope of finding any pertinent grey literature, such as policy documents or ongoing studies.

I limited the searches to English language publications and those printed since 1990 as I consider lay understanding to be a non-static phenomenon, influenced by and changed due to social and political time and place (Nettleton 1995, Fitzpatrick 1989, Williams and Popay 1994) making earlier work less relevant.

The majority of studies on lay understanding of cancer rely on surveys giving valuable numerical information. However, I chose to review studies that had employed or included qualitative methods (usually focus groups and interviews) and analysis as I believed these would enhance understanding about beliefs and the meaning people apply to them more comprehensively (Popay and Williams 1996).

A sizeable proportion of the primary research identified by the search had used research respondents already diagnosed with cancer. These were not included in my review as people who have experienced cancer are known to change their perceptions and beliefs about cancer as they undergo tests and treatment and are influenced more by biomedical understanding (Lipworth et al 2010, Del Castillo et al 2011). Furthermore, the majority of these studies concentrated on treatment decision making or illness identity rather than understanding about cancer per se. However, I did include people who had a family history of cancer, who may or may not have been referred to a cancer genetics service, as long as their risk remained undetermined (e.g. Sanders et al 2003, Kenen et al 2003[B], Thomas 2010). I also rejected the many articles that specifically explored *only* understanding of cancer genetics, genetic testing or screening, such as cervical smear testing, mammography and suspicious skin lesion testing (e.g. Blomberg et al 2009, Scott et al 2005, Walter et al 2010). I recognise that these are areas of major consideration within contemporary oncology but lay understanding and beliefs about them may be different to understanding

and beliefs of the disease itself and it was cancer I wished to give attention to. However, some studies that focused on these areas but also included data on general cancer understanding were included (e.g. Sanders et al 2003). Furthermore, I included studies that reviewed the lay understanding of other areas of ill health and healthcare if cancer was incorporated (for example, Walter and Emery 2005, who investigated the understanding of family history and risk of cancer, heart disease and diabetes and Lindenmeyer et al 2011, who explored narratives about health within families).

Although it was impractical to be too exclusive about the geographical source of the primary research, I am very aware that lay understanding of health and illness is culturally framed (Helman 2000) and therefore I was cautious of research that had taken place within societies that had very different cultural references and/or health care delivery as these may have impacted on the lay understanding of cancer and may not have been valid for this review. I decided to use research that had been generated from countries defined as 'high income' by the World Health Organisation (WHO 2010). However, I chose not to include studies on immigrants from other areas to 'high income' areas or indigenous populations who have a distinctive culture and history from the majority culture, such as Australian Aborigines or Native Americans, as these tended to highlight ethno-specific factors and concentrate on patient education (e.g. Prior 2009, Lui et al 2009, Canales et al 2011).

There is a small and interesting body of literature describing children's views on cancer (e.g. Oakley et al 1995, Williams and Bendelow 2000, Forrest et al 2006, Mosavel and El-Shaarawi 2007). For example, children and young people appear to have a comprehensive knowledge of cancer, particularly lung cancer and the risks of smoking (Oakley et al 1995), and persistently associate it with death (Forrest et al 2006, Mosavel and El-Shaarawi 2007).

However, children appear to differ considerably in their understanding of cancer causality depending on their age (Sigelman et al 1993) and Silk et al (2006) have shown a difference in adult and adolescent perceptions of breast cancer. Because of this and because my thesis is focused on adults, I decided to only include research using adult respondents within this review.

Inclusion criteria

- Research focusing on or relating to the lay understanding of cancer

- Research employing qualitative methods in all or some of study

- Research on adult respondents

- Research on people who do not have a cancer diagnosis

- Studies published between January 1st 1990 and December 31st 2011

- Studies published in English

- Research conducted on people living in WHO defined 'high income' areas

Exclusion criteria

- Research just focusing on lay understanding of cancer genetics, genetic testing or screening for cancer susceptibility

- Research employing quantitative methods only

- Research on children and young people (<18 years)

- Primary research on people diagnosed with cancer

- Literature published before 1990

- Research conducted on people living outside of the WHO defined 'high income' areas, immigrants from lower to 'high income' areas or indigenous people with a distinct culture from the majority culture

The numbers of articles identified, screened, included and excluded are outlined in Figure 1 'Information flow diagram'.

Figure 1: Information flow diagram (after PRISMA 2009)
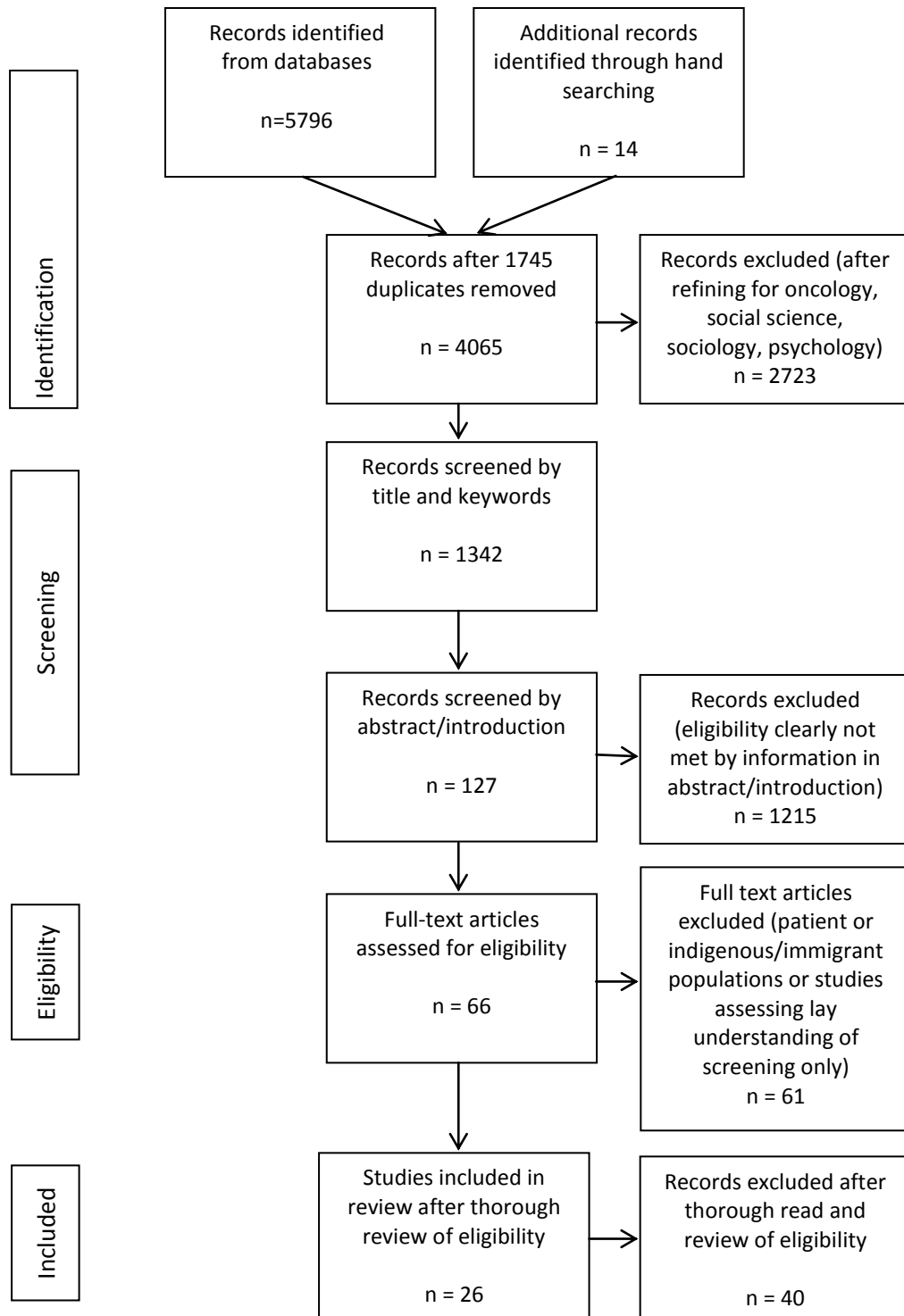
Method of appraisal and analysis

Twenty-six eligible studies were found as detailed in Table 1 overleaf 'Summary of eligible research retrieved'. Although critical appraisal is an important part of reviewing experimental studies and ensures that poorly designed trials in which bias is likely are excluded, there is a continued debate about how, or even whether, qualitative research should be assessed for quality (Atkins et al 2008, Thomas and Harden 2008) and which, if any, critical appraisal tools are 'fit for purpose' (Aveyard 2010). However, to ensure rigour, credibility and relevance, I appraised all the eligible articles using the NHS Public Health Research Unit's (PHRU) Critical Appraisal Skills Programme (CASP) Appraisal Tool (PHRU 2007) which is a commonly used means of reviewing health research, including qualitative studies (Campbell et al 2003, Walter et al 2004). Although some articles went into much more depth and detail than others, I considered that there was a broadly positive reply to each of the ten listed 'screening' and 'detailed' questions for all twenty-six studies and, as all had been published in high quality social science, medical or nursing journals (except one which was a comprehensive report produced by the Ulster Cancer Foundation and University of Ulster), I considered that no study should be rejected from the review on methodological criteria.

Table 1: Summary of eligible research retrieved

Authors & date	Where published	Stated aim of study	Sample & how recruited	Method of data collection	Setting	Notes
Armstrong & Murphy 2008	Social Science & Medicine	Explore interplay between lay & professional understanding of cervical cancer risk	35 women aged 20-64 recruited via community groups & snowballing in difficult to reach groups.	Interviews	East Midland, UK.	
Baron-Epel & Klin 2009	Oncology Nursing Forum	Identify beliefs & attitudes of cancer from a Jewish urban population	82 adults aged over 50	9 focus groups	Israel	
Chalmers & Thomson 1996	Qualitative Health Research	Explore & describe meaning of risk in women with primary relatives with breast cancer	55 women aged 20-70 recruited in various ways e.g. via index cases, responding to adverts & snowballing	Interviews	Canada	
Emslie et al 2001	Coronary Health Care	Explore lay beliefs of heart disease	61 adults aged 40-49 purposively sampled & recruited from a large epidemiological survey	Interviews	West of Scotland, UK	Perceptions of death from CHD compared with perceptions of death from cancer
Hallowell 2006	Health, Risk & Society	Explore understanding of risk in women with a family history of ovarian cancer	49 women aged 31-50 recruited via the UKCCCR Familial Ovarian Cancer Register & 2 cancer genetics clinics	Interviews	London, UK	
Han et al 2009	Health Expectations	Explore laypersons' understanding of cancer risk & identify conceptual problems that may limit understanding	48 adults aged 50-74, purposively sampled & recruited over the telephone by a professional recruiting service	8 focus groups	Washington DC & Chicago, USA	

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Heikkinen et al 2010	Social Science & Medicine	Examine accounts given by smokers in response to argument that smoking is a risk to health	55 current or former smokers recruited via workplace adverts & snowballing	Interviews	Finland	
Johnson & Dickson-Swift 2008	Health Education Journal	Explore young women's perceptions of breast cancer	6 female students aged 20-25 years recruited via university placed flyers & personal contacts	Interviews	Victoria, Australia	
Katapodi et al 2005	Social Science & Medicine	Identify heuristics that influence perceived breast cancer risks.	11 women who had experienced abnormal breast symptoms recruited via community survey of breast health behaviour	Interview	USA	
Kenen et al 2003	Sociology of Health & Illness	Explore how people from suspected hereditary breast & ovarian cancer families are influenced by family stories & heuristics in interpreting & applying genetic information	21 women referred to genetics service but with unknown status recruited from clinics	Interviews supplemented by observation of clinical encounter	UK	
Lindenmeyer et al 2008	Health	Explore how personal experience of ill health translates into vulnerability	69 women, minimum age 45 (not stated how many with experience of cancer) recruited in various ways e.g. via healthcare & community organisations	Interviews	UK	Some exploration of breast cancer experience
Lindenmeyer et al 2011	Health	Explore the definitions & understanding of family history held by lay people	10 people aged 51-69 recruited via urban library reading groups & adult education venues	Interviews	UK	Some exploration of family discussions about cancer
Lowry & Craven 1999	British Dental Journal	Examine perceptions & understanding of oral cancer among drinkers & smokers	27 male drinkers & smokers aged 45-60 recruited via market research interviewers on a door-to-door basis	3 focus groups	North East England, UK	

McAllister et al 1998	Journal of Medical Genetics	Describe attitudes & experiences of brothers of women with hereditary breast cancer	22 males aged 25-60 recruited via index cases.	Interviews	Dublin, Ireland	
McFall et al 2006	Patient Education & Counseling	Compare beliefs across 3 racial/ethnic categories about prostate cancer aetiology, risk, screening & decision-making	33 African Americans, 35 Hispanic & 22 non-Hispanic white men & women, mean age 54, recruited via adverts in clinics & clinical identification.	12 focus groups	Oklahoma & Houston, USA	
McKenna et al 2006	Ulster Cancer Foundation	Explore knowledge, attitudes & behaviours relating to cancer prevention measures.	Exact number not stated; adults aged 35-54 years recruited via letter from the Health and Social Services Boards in Northern Ireland	6 focus groups (qualitative part of study)	Northern Ireland, UK	'Grey' literature. Qualitative analysis reviewed only
Robb et al 2007	Cancer Epidemiology Biomarkers	Investigate perceived risk of developing colorectal cancer	16 adults aged 60-63 recruited via 2 urban GP practices & about to take part in a screening study for colorectal cancer (qualitative part of study)	Interviews (qualitative part of study)	South West England, UK	Qualitative analysis reviewed only
Salant & Gehlert 2008	Sociology of Health & Illness	Explore community understanding of breast cancer & breast cancer risk	Exact number not stated, predominantly African American adults recruited via community & local media adverts	18 focus groups (7-13 participants per group)	Chicago, USA	
Sanders et al 2003	Health, Risk & Society	Explore perceptions of heredity, genetics & risk.	24 first degree relatives of people with breast, colon or prostate cancer recruited via index cases	Interviews	UK	
Sanders et al 2007	Qualitative Health Research	Examine how people rationalise risk in relation to health problems	16 adults recruited from 4 GP practices	Interviews	UK	Some exploration of perceived cancer risk.

Scanlon et al 2006	Ethnicity & Health	Identify & explore explanatory models of cancer among Irish & white British people.	58 1st, 2nd or 3rd generation Irish & 57 white British adults aged 35-75 recruited via community, workplace, local media & cancer organisation adverts plus snowballing	Interviews & focus groups	London, Manchester & Glasgow, UK	
Sheikh & Ogden 1998	Patient Education & Counseling	Explore understanding of cancer & reasons for seeking help for symptoms	20 adults (qualitative part of study) recruited via an urban GP practice	Interviews (qualitative part of study)	UK	Qualitative analysis reviewed only
Silk et al 2006	Social Science & Medicine	Evaluate adolescent & adult females' understanding & perceptions of breast cancer & environmental factors	36 women (aged 21-55) & 55 girls (aged 9-15) recruited via a university, school & youth organisation	10 focus groups (including 4 'mother' groups)	USA	'Mother' & 'girl' groups analysed separately allowing just adult understanding to be reviewed here
Thomas 2010	American Journal of Nursing	Explore awareness & knowledge of male breast cancer among men	28 men aged at least 30 without breast cancer but with at least 1 maternal relative with breast cancer, recruited via flyers placed in local businesses, newspapers, churches & University of Colorado	Interviews	Denver, USA	
Walter & Emery 2005	Annals of Family Medicine	Explore how people understand & come to terms with their family history of cancer, heart disease or diabetes	30 adults with an identified family history (14 with cancer) recruited from 2 GP practices	Interviews	Cambridge, UK	
Walter & Emery 2006	Family Practice	Compare & contrast perceptions of family history across common diseases	30 adults with an identified family history (14 with cancer) recruited from 2 GP practices	Interviews	Cambridge, UK	

Method of analysis

Thomas and Harden's (2008) three-step thematic synthesis was used to guide analysis. Thematic synthesis was developed from a need to address questions of appropriateness and acceptability as well as effectiveness and in response to concerns that existing methods of synthesis may lack transparency because of a failure to differentiate between 'theory-driven' and 'data-driven' approaches (Dixon-Woods et al 2005, Thomas and Harden 2008). It combines and modifies aspects of meta-ethnography, in seeking to translate data and develop descriptive and analytical themes, and grounded theory, by being inductive and adopting line-by-line coding and constant comparison (Barnett-Page and Thomas 2009). A novel aspect of thematic synthesis is that it advocates the use of computer-assisted qualitative data analysis software (CAQDAS) to ensure thorough scrutiny of the data (Thomas and Harden 2008, Barnett-Page and Thomas 2009). I therefore uploaded data from the results or findings of the twenty-six studies from both the main reports and abstracts to the CAQDAS package NVivo8 and considered it in a three step process, comprising:

- Line-by-line coding into 'free' and 'tree' (with associated 'child') nodes.

- Organisation of these into descriptive key themes

- 'Going beyond' the content of the original studies in an attempt to generate additional understanding and analytical themes.

Results: Key themes identified

Six analytic themes were developed from a total of twenty three coded nodes, entitled:

- obtaining information

- identifying cancer

- causes of cancer

- personal risk

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- the social image of cancer

- dealing with cancer.

The themes identified and the nodes from which they were developed are illustrated in Table 2. There was some overlap, for example the free node '"sometimes you're lucky and sometimes you're not"' appeared to a lesser degree in 'causes of cancer' as well as 'personal risk' and 'fear' touched on many themes but any overlap was quite limited. The majority of the research analysed came from a health education perspective and available data was greatest for perceptions of cancer cause and risk.

Table 2: Key themes identified and nodes from which they evolved

Themes	Tree nodes *(& associated child nodes)*	Free nodes
Obtaining information	Information sources – (*Targeting information, Interpretation of biomedical understanding*)	Witnessing cancer Suspicion of biomedicine
Identifying cancer	Symptoms	Detecting cancer Several distinct diseases What is cancer? Fatalism
Causes of cancer	Causes – (*"Bad blood", Contagion, Gender, Environment, Ethnicity, Lifestyle, Nostalgia, Stereotype, Trauma*) Age – (*Disease of older people, Childbirth as precursor, Menopause as precursor*)	
Personal risk	Interpretation of risk – (*Bargaining, Over-estimation, Under-estimation*) Proximity – (*Memory, Resemblance*)	"Sometimes you're lucky and sometimes you're not" "A gamble"
The social image of cancer	Death – (*"Slow and lingering", Social death*)	Images of cancer Shame and blame 'Good' and 'bad' cancers Fear
Dealing with cancer	"The risk of knowing"	Gender specific Communication Choice "Backburner" Challenge

Obtaining information

"There is no quality advice ... so you find your own solutions"

<div align="right">participant in study by Lowry & Craven 1999.</div>

Many of the studies that had investigated lay constructions of cancer risk (e.g. Sanders et al 2003, Hallowell 2006, Katapodi et al 2005, Robb et al 2007, Salant and Gehlert 2008) had also considered the information sources accessed. The predominant sources contributing to lay understanding appeared to come from family members and social networks, which included friends, peers and public figures diagnosed with cancer. Witnessing the cancer treatment and sometimes death of someone close was always seen to be the most reliable source of experience and knowledge, although Scanlon and colleagues (2006) recognised that this may lead to a lassaiz-faire attitude about cancer risk in people with less personal exposure, such as younger people. Other cited information sources were the media, including television, the internet, books and newspapers. Media sources were seen as most reliable by younger people, such as the young women in Johnson and Dickson-Swift's (2008) study. However, there was often debate about the trustworthiness of such information by respondents (e.g. McKenna et al 2006).

The experience of family members and friends was often quoted as 'counter evidence' to biomedical information (Heikinnen et al 2010). In fact, information sourced from health professionals came up against the most criticism from participants, being seen as inconsistent (Lowry and Craven 1999), unreliable (Mckenna et al 2006), causing misunderstanding (Kenen et al 2003[B], Armstrong and Murphy 2008) or being unavailable (Thomas 2010). Two African American participants in Salant & Gehlert's (2008) study talked of a historical "cultural aversion to doctors" and "distrust for the medical system", which

stemmed from most doctors being white and therefore "insensitive to the needs of black folks" and affirmed by, for example, the Tuskagee experiments (Jones 1989).

Identifying cancer

"If you have a lump and it hurts, it is not cancerous"

participant in study by Silk et al 2006.

Understanding of the signs and symptoms of cancer was often unspecific. Quotes such as "Lumps anywhere they shouldn't be" and "blood from anywhere it shouldn't be" (participant from Sheikh and Ogden's 1998 study) were fairly universally cited but there was little discussion about symptoms specific to different types of cancer and some populations admitting that they were unsure and lacked knowledge about this. Furthermore there was some confusion about the nature of symptoms, for example whether painful 'lumps' were something to worry about or not (Silk et al 2006, Katapodi et al 2005, Thomas 2010). Some studies detected a gender differential, with women usually more confident in their knowledge of symptoms than men (e.g. Scanlon et al 2006, McKenna et al 2006).

Self-examination and screening were generally seen as reliable ways of detecting cancer and "buying yourself a bit more life" (participant in Sheikh and Ogden's 1998 study) although many admitted not doing this. Screening was sometimes seen as something you started when symptoms became apparent rather than before.

Whether cancer was seen as a single disease or many distinct diseases differed between studies. Those populations that understood it as more than one disease, also differentiated between 'good' cancers with identifiable symptoms which could be detected quickly and

'bad' cancers with unspecific or discrete symptoms which were therefore diagnosed late and inevitably led to death (Katapodi et al 2005, Scanlon et al 2006).

Causes of cancer

"Some would say it's your karma, some would say the cards have been dealt, some would say it's a gene gone mad, some say it's life's tale"

participant in study by Kenen et al 2003[B].

The majority of participants in the studies described causation in complex ways. Cancer was often seen as inherent and just waiting for a causative 'trigger'. The most cited causes were hereditary factors, increasing age, lifestyle and environmental factors (smoking, exercise, diet, sexual activity, pollution) and trauma or infection.

The preponderance of hereditary factors identified may have been biased by Kenen and colleagues' (2003[B]) study of genetic service attendees and others whose participants had been drawn from family members of people with cancer (Sanders et al 2003, MacAllistair et al 1998 and Chalmers and Thomson 1996). However, participants in the majority of studies referred to hereditary factors or 'bad blood' as a cause and more so than other factors. Their explanations were often hesitant and described with uncertainly. For example, a woman in Kenen et al's (2003[B]) study talked about "something in the family blood flow that gives everyone this little bit of cancer", participants in Robb et al's (2007) study described cancer risk missing generations or favouring genders: "the genes of my father go through the females in our family" and a man in Sanders et al's (2003) study explained that his genetic risk would have been greater if his father had had cancer, rather than his brother. Despite being certain that cancer often had a genetic causation, the concept that a cancer risk may be hereditary or familial appeared to be hard to acknowledge for both

people with a family member with cancer and those without. Sanders et al (2003), MacAllistair et al (1998) and Kenen et al (2003[B]) all described participants who referred to other causes to explain their relative's cancer, such as lifestyle, non-adherence to screening, trauma or shock, rather than concede genetic factors. Often, the *lack* of a family history was seen as a reassuring protection against cancer (Lindenmeyer et al 2011).

Many participants identified increasing age as a cause of cancer, although often secondary to hereditary factors, as illustrated by one of Lindenmeyer et al's (2008) participants, who said "suddenly, in their eighties and nineties, relatives have got it. We didn't have cancer in the family now I'm thinking, oh it's started, so therefore – you know, is there a risk?" The age at which screening is recommended to start seemed to reflect the age at which cancer was seen to become a risk and participants talked of planning to reduce other causative factors, such as losing weight, when they reached that age. Being diagnosed with cancer in old age was seen as a "good innings" (participant in Walter and Emery's 2006 study describing a diagnosis in somebody's eighties). Certain age-related milestones were also seen as times when the body was vulnerable, for example, Armstrong and Murphy's (2008) participants recognised the menopause when "things can happen in your balance and everything is upset" as a particularly risky time. Youth was seen as a protection against cancer for many participants in the studies.

Nearly half of the men in Thomas' (2010) study about men's knowledge of breast cancer associated it directly with gender and felt their masculinity would be affected if they were to be diagnosed with it. As one man reported, "I wouldn't tell anyone, I would be afraid of the stigma" and another said, "masculine men most likely will not get breast cancer, only men with feminine tendencies".

Understanding related to what were regarded as lifestyle causes of cancer was often complex and ambiguous. Many participants in the studies had a stereotypical image of someone who would be likely to develop cancer – often people who were sedentary, poorly-educated, 'worriers' and/or who ate 'unhealthy' diets - and felt they could exert some control over their cancer risk through avoiding certain lifestyle choices. However, many knew of people with cancer who did not fit the stereotype, which seemed to confuse their picture. Diet was often mentioned as a cause or protecting factor and the past was described nostalgically when food was perceived to be fresher and less adulterated and cancer was less often reported or known about (and therefore assumed to be less present). Smoking and alcohol were infrequently mentioned. People who did smoke and/or drink usually mentioned these as causes but often related it to a greater consumption than theirs. Risks and benefits of lifestyle choices were often discussed, for example, whether it was better to embrace or avoid a 'pub culture' involving drinking and smoking but increasing a sense of belonging and escapism (Lowry and Craven 1999, Scanlon et al 2006), to control food intake by smoking and therefore risk dying of smoking-related cancer or to stop smoking and be "fat" and therefore, in one participant's view, socially unacceptable (Heikkinnen et al 2010) or to take HRT and risk breast cancer or not take it and risk osteoporosis (Lindenmeyer et al 2008). The modern environment (for example, when discussing food additives) was sometimes seen as a cause. Two studies (Salant and Gehlert 2008, Scanlon et al 2006) identified a belief that higher cancer diagnoses in ethnic groups was due to the geographical areas in which these populations lived and worked being more polluted than other areas.

Trauma, either physical (such as a blow to the breast) or emotional and infections, such as a cold, were also cited as causes of cancer. This was related to the belief that cancer was

innate and just needed something to trigger it off and was often used to explain cancer occurring in the non-stereotypical person.

Interpreting personal risk

"I'm much more like my Dad's side ... they live real long"

<div align="right">participant in study by McAllister et al 1998.</div>

The ambivalence expressed when relating the causes of cancer recurred when participants talked about their own personal risk and, of the studies that looked into this, a greater number of participants were optimistically biased about their risk of developing cancer. Participants appeared to distance themselves from risks they were aware of, for example, the risks of smoking were counteracted with 'healthy behaviour', such as exercising (Heikinnen et al 2010), palpable breast lumps were assessed as vague breast changes (Katapodi et al 2005) and hereditary risk was lessened by healthy eating (Kenen et al 2003[B]). A participant in Lindenmeyer et al's (2011) study admitted not attending for breast screening because she felt her family history of heart disease was a greater risk and this had made her complacent about any breast cancer risk.

The awareness or memory of a quick or 'difficult' cancer death appeared to heighten risk perception (Kenen et al 2003[B]) but the factor that seemed to have the greatest influence on a personal interpretation of risk was an individual's resemblance to a family member with a cancer diagnosis. This was apparent in several studies (Kenen et al 2003[B], Lindenmeyer et al 2008, McAllistair et al 1998, Sanders et al 2007, Sanders et al 2003, Walter and Emery 2005) and accounted for physical resemblance as well as personality and mannerisms. Conversely, distinction in looks or characteristics lessened the risk. A participant in Kenen et al's (2003[B]) study reported taking her son to see his great aunt

when she was very sick with cancer and saying to him, "there's you in that bed, even your faces look alike" in an attempt to stop him smoking, even though she reported that she did not believe that looking like someone meant you were more likely to develop 'their' cancer.

The social image of cancer

"I think when you hear the word cancer it seems to hit you between the eyes … you hear about other diseases, that can be just as bad, but there is something about cancer"

<div align="right">participant in Study by Sheikh and Ogden 1998.</div>

Cancer was repeatedly described as an aberration and something to be feared and participants in the studies by Baron-Epel and Klin (2009), Lowry and Craven 1999, McAllistair et al 1998, Salant and Gehlert (2008), Scanlon et al (2006), Sheikh and Ogden (1998), Silk et al (2006), McKenna et al (2006), Walter and Emery (2005), Walter and Emery (2006) and Lindenmeyer et al (2011) all mentioned this. Although it was generally appreciated that treatments had improved and cancer being an "automatic death sentence" (participant in Salant and Gehlert's 2008 study) was a thing of the past, the "cancer equals death" (participant in Scanlon et al's 2006 study) equation was still pervasive. Salant and Gehlert (2008), Sheikh and Ogden (1998), Silk et al (2006), Scanlon et al (2006) and Walter and Emery (2005) all reported participants for whom the fear of cancer was so great it actually prevented self-examination or information seeking.

Cancer evoked more fear and loss of control than other chronic, life-threatening diseases, such as heart disease or diabetes (Emslie et al 2001, Walter and Emery 2006) and death from it was seen as much more inevitable and somehow worse. 'Quick' deaths following heart attacks or trauma were contrasted with images of the perceived protracted and painful deaths of cancer. Participants recalled friends and relatives "fighting for every

breath, wanting an extra day all the while" and ending up in a "pitiful state" (participants in Hallowell's 2006 study) and even participants who had not witnessed cancer imagined sufferers "dying inch by inch" (participant in Sheikh and Ogden's 1998 study). Hallowell (2006) also detected what she termed a 'social death' in her participants' understanding of an ovarian cancer death which entailed a loss of familial obligations and fulfilment (e.g. seeing children grow-up, enjoying retirement) as well as a loss or severing of relationships prior to death.

The image of cancer as shameful or a personal weakness was also strong for many of the study populations and was inherent in the way people were often unable to name or talk about it (Kenen et al 2003[B], MacAllistair et al 1998, Salant and Gehlert 2008, Scanlon et al 2006, Lowry and Craven 1999). This was illustrated by a women in Walter and Emery's (2006) study who talked about "the *punishment* of pain" associated with cancer (emphasis added).

Dealing with cancer

"You are thinking about providing food for your children – whether or not you are going to have shelter, with the economy being the way it is now, cancer sits on the back burner. It only comes up when it becomes personal"

participant in study by Salant et al 2008.

Cancer was rarely addressed in day-to-day life. In fact, there were many instances of active avoidance of any acknowledgement of its presence (McKenna et al 2006, Sheikh and Ogden 1998, Scanlon et al 2006, Sanders et al 2003, Salant and Gehlert 2008, MacAllistair et al 1998, Lowry and Craven 1999, Kenen et al 2003[B]). For example, a participant in the study by Sanders and colleagues (2003) explained, "I just wouldn't want to think about it. Why

should I? Because I think if you did, my goodness me, you'd be down that road. I can't afford to think like that, I've got enough to do…" even though she had a sister with breast cancer. This could be frustrating for some people who felt they needed more family information to determine personal risk (e.g. some women in Kenen et al's 2003[B] study) or political recognition (e.g. some of the mainly African American participants in Salant and Gehlert's 2008 study). However, worrying about cancer was generally seen as getting in the way of more important concerns. Salant and Gehlert (2008) even proposed that for their sample, dwelling on cancer was seen to risk increasing anxiety and therefore causing it.

'Dealing with cancer' was also seen as a gendered activity with male participants reporting that women were more likely to both consider their risk and talk about cancer. It was suggested that this was because women were more aware due to female targeted screening (McKenna et al 2006) or that cancer and other illnesses were seen as a weakness in male culture (Scanlon et al 2006) but men also reported that they were busier and more occupied, for example with paid work, to get involved with thinking about cancer (MacAllistair et al 1998). Some of the largely African American participants in Salant and Gehlert's 2008 study felt that addressing cancer was almost a luxury that could not be afforded by the less advantaged.

Discussion

To enhance the validity of my analysis I followed an approach known as thematic synthesis which has been used frequently and proved to be useful in assimilating qualitative research (Thomas and Harden 2008). I found that this was a straightforward framework to apply and allowed a thorough investigation and integration of all the identified studies. The use of CAQDAS made the process of retrieving and scrutinising data exhaustive but uncomplicated.

In common with other sociological work on health beliefs, the analytical key themes I have identified from this review reveal a significant complexity in lay knowledge of cancer, particularly concerning the understanding of the causes of cancer and the interpretation of personal risk (Fitzpatrick 1989, Blaxter 1983).

In accordance with Davison et al's (1991) concept of 'lay epidemiology', the participants felt the most reliable source of knowledge about cancer came from individuals with it (either personally known or reported about). As Davison and colleagues explain, the experiences and circumstances of such people seem to contribute to explanations which may challenge biomedical accounts.

Many people played the risk of cancer down believing personal lifestyle choices would prevent it and others (who fit a certain stereotype) would get it. This is similarly explored in the important and often quoted work on the lay understanding of coronary heart disease prevention by Davison and colleagues (Davison et al 1991, Davison et al 1992). They describe how people identify 'candidates' who they believe are more at risk of developing heart disease and this notion of 'candidacy' provides a mechanism whereby they can assess their own risk (usually reassuringly), formulate strategies to decrease that risk and explain distressing events. Davison and colleagues also note that people are happy to incorporate a certain amount of fallibility into the concept of candidacy as this allows for it to only indicate an increased *risk* while death remains random (Davison et al 1991). This is also seen in the analytical themes identified here. Participants recognised that 'non-stereotypical' people could receive a cancer diagnosis and that some causes had a certain randomness, such as trauma or an emotional reaction to a stressful event.

Although hereditary factors were seen within these studies as the most common cause of cancer, a genetic or familial tendency was often difficult to accept. An explanation is offered by Hallowell (1999) who argues that the 'geneticisation' of cancer has led to the re-categorisation of healthy people as 'at risk' and with an inherent responsibility towards both themselves and future generations and an obligation to manage their risk. This may cause unwanted anxiety for people and possibly affect disadvantaged populations to a greater extent (such as Salant and Gehlert's participants) as they feel they have less opportunity to address such things (Nettleton 1995). Another explanation may be the stigma that persists around cancer (Sontag 1991, Stacey 1997, Mathieson and Stam 1995). Although it is more than thirty years since Sontag first described how the metaphors and myths surrounding cancer can add greatly to the burden of people with it and may inhibit them from seeking a diagnosis, cancer still appears to hold a great deal of stigma within society that affects those with it and those close to them and continues to be referred to as "the 'Big C'" (participant in study by Sheikh and Ogden 1998) (Sontag 1991, Wilson and Luker 2006, Chapple et al 2004, Rosman 2004). This may possibly extend to those considered 'at risk' by themselves or others. For example, Lindenmeyer et al (2011) describe cancer being prominent in their study of health talk in families but excluded from narratives of inheritance, which they suggest is due to the enduring stigma attached to cancer.

Similarly, Sontag's claim that a diagnosis of cancer equates with a death sentence seems to persist despite the advances in treatment and survival in the last thirty years (Sontag 1991). Furthermore, the images participants had of a cancer death were horrific and frightening and, in the case of Hallowell's (2006) participants, somehow greater than a physical death.

Strengths and weaknesses of review

This review is drawn from twenty-six articles employing qualitative methods and published in good quality journals (and one university publication). They were identified via both a database and hand search using a multiplicity of search terms relating to lay knowledge and cancer. I believe that I identified most of the relevant and eligible articles as the same ones appeared repeatedly in the databases, however this highlights the paucity of published studies that specifically address lay knowledge of cancer in the populations I investigated. This may reflect Blaxter's assertion, from her study of women's explanations for the causes of illness, that although it was frequently mentioned it was rarely discussed as though "to talk about it was to invoke it" (Blaxter 1983, p67).

Although, class and gender issues were alluded to within the participants' responses, it is difficult to draw any firm conclusions from this review due to insufficient information about the study samples, the bias of solely female samples to solely male (8:4) and the different disease sites these represented.

Although, some studies were descriptive and sought to explore how lay understanding is framed, created and incorporated (for example, Hallowell 2006, Armstrong and Murphy 2008), the majority were written from a health promotion viewpoint and were explicit in their aim of motivating compliance with screening and adherence to healthy behaviour (for example, Johnson and Dickson-Swift 2008, Baron-Epel and Klin 2009). This gave them an educative standpoint and seemingly an underlying assumption of biomedical knowledge as 'right' and lay knowledge as 'wrong' and to be corrected. For example, Kenen and colleagues describe widespread "misconceptions" in their population (Kenen et al 2003[B], p849) and Johnson and Dickson-Swift talk about their young women having "very low levels of knowledge about breast cancer" and the need to "increase knowledge and adherence"

(Johnson and Dickson-Swift 2008, p253). This is contrary to the sociological paradigm of lay knowledge and may have influenced the published results and conclusions of those studies. It may also have influenced the areas of lay knowledge reported. For example, the causes of cancer and understanding of personal risk were highly represented in the studies but there was no information found about lay knowledge of cancer treatment and, although there was mention in two studies that people understood that cancer comprised many different diseases, this was not explicitly discussed or clarified.

Conclusion

Although cancer affects a large proportion of individuals living in 'high income' countries, only a relatively small number of qualitative studies exist that have comprehensively examined lay knowledge of cancer. However, this review has identified several recurrent key themes from the existing literature concerning people's understanding of the causes, identification and risk of cancer and how people deal with (or ignore) these. It has also identified some cultural images surrounding cancer and where and how lay knowledge may develop. These are important as they provide detailed understanding, frame perception and form a basis of what is known about cancer within society and lay communities. This review has also highlighted the need for additional work, particularly in gaining an understanding of the stigma and fear that surrounds this common disease, which may in turn inform clinical staff and help patients and those close to them live successfully with and beyond cancer.

The following chapter will describe the methodology I have chosen to adopt for my empirical work.

World Health Organisation defined 'high income' countries (WHO 2010).

Andorra, Antigua and Barbuda, Australia, Austria, Bahamas, Bahrain, Barbados, Belgium, Brunei, Darussalam, Canada, Croatia, Cyprus, Czech Republic, Denmark, Equatorial Guinea, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Japan, Kuwait, Luxembourg, Malta, Monaco, Netherlands, New Zealand, Norway, Oman, Portugal, Qatar, Republic of Korea, San Marino, Saudi Arabia, Singapore, Slovakia, Slovenia, Spain, Sweden, Switzerland, Trinidad and Tobago, United Arab Emirates, United Kingdom, United States of America.

Chapter 4

Participant-produced photography in health and illness research:

methodology and application

Introduction

In my principal study I used a visual and participatory research method, known as photovoice to gather data. Photovoice is a photo-interviewing technique which uses participant-produced photographs and interview narrative to illustrate and explore phenomena. In this chapter, I will present a brief history of the use photography in social science research, discuss the ontological, epistemological and methodological assumptions behind photo-interviewing methods and explain why this was an appropriate method to employ in this case. I will also examine some of the issues that need to be considered when using such methods, including legal and ethical concerns.

Background: 'Seeing' health and illness

Vision is the most highly developed human sense and as Hugh Crawford (1998) and Baldwin et al (1999) suggest, it seems to be afforded a great certainty or truth, as evident in everyday maxims such as 'seeing is believing', 'had to see it with my own eyes' or 'staring you in the face'. As Pink (2007, p21) explains, "images are everywhere" and without them we would be unable to describe our work, social lives, conversations, identities, dreams, culture or history. There has also been a progressive and pervasive adoption of visual imagery and representation within postmodern society and it is one of the most important ways in which meaning is conveyed within our culture (Hall 1997, Harrison 2002[A and B], Mizen and Wolkowitz 2006, Rose 2007, Prosser and Loxley 2008). In particular, visual representations provide a powerful medium through which beliefs and concepts about the body and its cultural, political and social relationships can be expressed and emphasised

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(Williams and Bendelow 1998). For instance, cancer, being associated with both drama and metaphor (Sontag 1991, Lupton 1994[B&C], Stacey 1997), is highly visible in films and television (Lupton 199[B&C], Clark 2004, Fernández-Morales 2009) and a study by Johnson and Meischke (1994) found that television was the preferred media source of cancer information for women. However, the representations offered may be biased (Hugh Crawford 1998, Lederer 2007). For example, in Clark's (2004) review of twentieth century American films that portrayed cancer, half the 'patients' were under thirty and common cancers were rarely depicted. Instead, cancers such as leukemia and brain tumors predominated because they were considered 'clean'. Smoking-related cancers were virtually absent because, he argues, cigarettes and smoking have always signified sexiness and atmosphere in films and have become important income generators in the form of product placement.

There are also many examples of people who have lived with ill health and have portrayed their personal experiences through visual media, such as Frida Kahlo who used art to represent her lifelong physical and psychological suffering after childhood polio and a serious traumatic spinal injury (Sandblom 1992, Williams and Bendelow 1998). Some of the first cancer specific artistic representations include portraits of women with identifiable breast cancer painted in the sixteenth and seventeenth centuries (Grau and Estrach 2008). Recent examples include what Tembeck (2008) has termed, 'autopathographical performativity' or first-hand narratives of illness and suffering in visual form, such as the work of the British photographer and activist Jo Spence. Spence was a Marxist and feminist artist who came to recognition in the 1970s with her work using photography to document and explore the lives of women at home and caring for children (Bell 2002, Tembeck 2008). In 1982 she was diagnosed with breast cancer and her work shifted from an exploration of class and gender based group identities to a more personal examination of individual

subjectivity, particularly around issues of health and illness, power relationships in Western health systems and the creation of passive 'patients' (Tembeck 2008, Bell 2002, Bell 2006). For the ten years before her death in 1992, she continued to produce and exhibit her work, conveying her own meaning but also representing a sensibility about breast cancer for women generally (Radley and Bell 2007). More contemporary examples of visual narratives of cancer experience include the work by The Creative Center in New York that has produced a book entitled 'Still Life' which portrays the experience of cancer survival through the photographs by twenty-five amateur photographers who have cancer diagnoses (The Creative Center 2006).

The development of photography in social science research

Spence's work is an example of the long sociological and anthropological tradition of using photography to capture, record and express the social world (Becker 1974, Prosser and Loxley 2008). However, until recently, photography and other visual media have been largely disregarded by researchers who have tended to translate observations into numbers and words (Prosser 1996, Harrison 2002[A and B]). Although vision is recognised as one of the major ways in which we understand the world, it has been argued that an ambivalence has often existed towards it, with the visual often being associated with subjectivity and persuasion whereas text is allied to science and impartiality (Prosser 1996, Holliday 2000, Harrison 2002[A], Sandelowski 2002, Wagner 2004, Epstein et al 2006, Frith et al 2005, Prosser and Loxley 2008). Nevertheless, over the past fifty years, some social researchers have made an increasingly strong case for the use of visual methods in research (Becker 1974, Hurworth 2003, Guillemin 2004, Wiles et al 2008) and journals such as 'Symbolic Interaction' have expressed interest in publishing studies based on visual methods (Harper 1988) It has been suggested that one reason for this has been the development of photography and other visual technologies (Harrison 2002). Photography is

arguably a more egalitarian, accepted and even expected part of contemporary social events and everyday life (Sontag 1979, Guillemin and Drew 2010, Mitchell 2011). The recent rapid growth in digital technology and home computing have greatly enhanced the capacity to create, share and display photographs which have become an important tool in giving meaning to relationships and experience (Warren 2005, Mizen & Wolkowitz 2006, Guillemin and Drew 2010, Mitchell 2011). Another important influence has been the adoption of postmodernism, critical theory and cultural studies within social science, whereby visual representations are recognised as important communicators of socially contextualised information (Harper 1988, Harrison 2002[B], Rose 2007, Prosser and Loxley 2008, Packard 2008, Mannay 2010).

Visual approaches in research

Visual approaches employed in research and incorporating photography can broadly be placed within four categories (Warren 2005):

- Images as data

  For example, visual signs and symbols that provide insights into the culture, group or individual that produced them.

- Images as a record

  These are usually associated with the anthropology. They cover a broad range of documentary image making and have roots in realism, which sees photographs as representational rather than constructed.

- Images as stimuli to elicit information from research participants

  Although the late nineteenth century anthropologist, Franz Boas, reportedly showed photographs to Pacific Islanders to encourage them to describe their social rituals (Hurworth 2003), this technique, known as 'photo elicitation', has been credited to the American anthropologist John Collier Junior who developed it

during the 1960s. Photographs which are of significance to the participant are shown during an interview to encourage a dialogue between the researcher and participant about an event or experience (Pink 2007, Frith and Harcourt 2007, Oliffe and Bottorff 2007, Keller et al 2008). Collier used it to research how ethnically diverse communities live together after economic migration and he found that photographs encouraged a more open dialogue about socially and politically sensitive topics (Harper 2002, Hurworth 2003, Epstein et al 2006).

- Images as an aid to verbal narrative or in place of it, allowing research participants to express their own experience, beliefs, opinions, etc.

For the purpose of this thesis, I am focusing on the fourth category, which encompasses photographs created by the research participants themselves and is usually known by the term 'photo-interviewing'. Hurworth et al (2005) and Warren (2005) describe three subtly different types of photo-interview: 'auto-driving' whereby any discussion is 'driven' by the participant's own chosen images, 'reflexive photography' in which the conversations about the photograph generate the data and 'photovoice', which was developed specifically for use in health and social care and was designed to be empowering for participants.

Caroline Wang and Mary Burris developed 'photovoice' (which they originally named 'photo novella') in the 1990s as a means of empowering the rural Chinese women they were working with to influence the health policies and programs that affected them. It derives from Paulo Freire's educational approach which emphasises the importance of people talking about and learning from their own experiences, feminist theory which actively seeks to remove the power imbalance between research and participant and aims to change social inequality and action research which stresses the involvement of participants in the process of changing their situation (Bowling 1997, Keller et al 2008).

Photovoice involves recruiting a group of participants who will create their own photographs to portray a particular theme or experience and then select and discuss the significant ones to illustrate pertinent issues and it has become a rapidly growing technique in health and social care visual research (Wang and Burris 1994, Wang & Burris 1997, Catalani and Minkler 2010). Photovoice has three central goals (Wang and Burris 1997, Hurman 2003), which are to:

- enable people to record and reflect concerns

- promote critical dialogue and knowledge about important issues through discussion of photographs

- empower research participants to reach and directly influence policymakers.

Initially Wang and Burris advocated the communal basis of photovoice and the engagement of *all* participants in group discussions and presentation of images (Wang and Redwood-Jones 2001) but it has often been necessary to modify the method to incorporate people's physical or travel limitations and the impracticality of attending group sessions (Baker and Wang 2006, Catalani and Minkler 2010). As Castleden et al (2008) argue, such community based participatory research methods need to be flexible to 'fit' the community that is being researched. Therefore, the creation and discussion of images sometimes takes place on an individual basis. For example, Baker and Wang modified their method to explore the experience of chronic pain with thirteen adults who did not meet each other; instead interviews took place on a one-to-one basis (Baker and Wang 2006, Catalani and Minkler 2010).

Although still a developing methodology, photo-interviewing techniques, such as photovoice, have been used successfully in previous studies to elucidate the meaning of cancer diagnosis and treatment (Epstein et al 2006; Frith & Harcourt 2007; Oliffe & Bottorff

2007) or cancer survival (López 2005; Poudrier & Maclean 2009; Yi & Zebrack 2010) but such research is so far limited to a small number of cancer sites or specific populations.

The methodological basis of photo-interviewing techniques

Because of its relative newness, methodological discussion specific to participant-produced photographs and photo-interviewing techniques is in short supply and requires more deliberation and consolidation (Guillemin and Drew 2010). Here, I outline visual research methodologies in general, followed by an introduction to their rudimentary development in photo-interviewing.

Background: Research paradigms and assumptions

The philosophical bases behind different modes of research may be categorised into 'paradigms'; a term first coined by the historian and philosopher Thomas Kuhn in the 1960s (Clark 1998, Paley 2000). A paradigm is an academic and/or professional consensus about the assumptions, theories and standards of research (Creswell 1994, Clark 1998, Bryman 2008). Different paradigms lead to differing opinions about what reality is (ontology), ways of establishing what is accepted as real (epistemology), strategies for validating and verifying claims (methodology) and techniques for collecting evidence about such claims (methods). Different ontological and epistemological principles are generally perceived to lie on a continuum with 'positivism' at one end and 'anti-positivism' or 'naturalism' at the other (Creswell 1994, Mason 1996, Rolfe 2006, Hansen-Ketchum and Myrick 2008, Spencer 2011). Positivism signifies 'real' or actual existence and was introduced by the French philosopher Auguste Comte in 1830 (Williams 1989). Comte believed that the same methodology should be applied to the study of people and society as to the study of natural science. Positivists therefore assume that truths are objective, argue that reality can only be demonstrated through empirical evidence and explain phenomena using

scientific hypotheses and theory built in a linear and methodical way (Bilton et al 1987, Bowling 1997, Paley 2000, Bryman 2008). At the other end of the spectrum is anti-positivism which includes theoretical traditions such as interpretivism, constructivism and social action theory (Bilton et al 1987, Bowling 1997). Its roots lie in nineteenth century German philosophy and social science, when academics such as Sombart and Weber were concerned with distinguishing 'human' or 'cultural' sciences from natural sciences. For example, Sombart was concerned with "grasping the meaning" of an individual's experience of the world (Bilton et al 1987, p512). Thus, anti-positivists accept a subjective and socially constructed world with no definite and unequivocal reality (Proctor 1998, Paley 2000). As Hughes (1976) explains, "Human beings are not 'things' to be studied in the way one studies rats, plants or rocks, but are valuing, meaning-attributing beings ... To impose positivistic meanings upon the realm of social phenomena is to distort the fundamental nature of human existence" (quoted in Bilton et al 1987, p512).

Different ontological and epistemological philosophies require different research methodologies for the appropriate justification of their claims (Bowling 1997, Proctor 1998, Rolfe 2006, Bryman 2008). As Carr (1994) explains, deductive approaches, allied to positivism, are essentially objective and formal. An initial hypothesis is tested by collecting and analysing appropriate data and researchers should be detached in the belief that this will prevent bias and ensure impartiality. Deductive approaches include experimental designs and use methods that gather numerical, quantitative data such as randomised controlled trials and surveys. However, inductive approaches, allied to anti-positivism, require observations from which general statements, ideas and theories can be built (Rolfe 2006). Bilton et al (1987) describe anti-positivism as being subjective and the product of meaningful social interaction. As such, inductive approaches recognize that researchers must place themselves within the research setting in order to fully understand and

appreciate the situation. Inductive approaches include symbolic interactionism, ethnomethodology, grounded theory and action research and use methods that gather descriptive, qualitative data such as participant observation and unstructured interviews (Bilton et al 1987, Carr 1994, Baillie 1995, Bowling 1997, Koch and Harrington 1998). However, as Prosser (1996), Silver (2000) and Rolfe (2006) suggest, methodology is in itself never fixed and remains in a state of flux and the polarisation between quantitative and qualitative approaches is arguably becoming less distinct. For example, Hammersley says that to "retreat into paradigms effectively stultifies debate and hampers progress" (Hammersley 1992, p192).

Advocates of deductive research claim that it provides enough information about the variables under investigation to predict future outcomes and deductive studies are considered more consistent and repeatable (or reliable) because they are designed to control or eradicate extraneous variables (Bowling 1997, Koch and Harrington 1998). However, this reliability is questionable when data is taken away from its natural context or when so called insignificant events are assumed not to have occurred (Carr 1994). Validity or 'truth' (Bilton et al 1987) is then difficult to ascertain in deductive research because the greater control makes it harder to confirm that the research situation is "like real life" (Carr 1994, p719). Inductive approaches such as symbolic interactionism, grounded theory, phenomenology and ethnography allow flexibility and a more genuine and profound understanding of participants, in which individual experience does not 'get lost' (Bilton et al 1987, Carr 1994) but the researcher's presence within the research setting may arguably introduce bias and distort results (Carr 1994, Laugharne 1995). However, because subjects are studied in their natural setting and encounter fewer controls, Carr (1994) suggests that there are fewer threats to validity with inductive methodology. Indeed, symbolic interactionists consider that immersion in the participants' own worlds and attempting to

recognize and build upon interaction with them (rather than trying to reduce and control it) is the most effective way of achieving knowledge (Miller and Glassner 1997).

When studying phenomena such as human experience and the meaning of what it is like to be diagnosed with and live with an illness, it is arguably more appropriate to use a naturalistic, inductive approach, such as symbolic interactionism, which is:

- Grounded in a paradigm that is broadly 'interpretivist' in that it is concerned with how the world is interpreted, understood, experienced and reproduced

- Based on flexible methods of data collection or generation which are sensitive to the social context in which they are produced

- Focused on methods of analysis and description that appreciate complexity, detail and context

Mason 1996, Bowling 1997, Silverman 2000.

Visual qualitative methodologies

Research involving photography has its roots in early anthropological and environmental sciences and images were originally used to quantify phenomena (Hansen-Ketchum and Myrick 2008). Prosser and Loxley (2008) explain that prior to the 1960s a schism existed between numbers-based positivist approaches and words-based interpretive or symbolic interactive approaches which prohibited the development of visual sociology or anthropology. However, in line with the development of critical and cultural studies, this began to grow as a separate reflexive and interpretive discipline from the mid-1960s. As Spencer (2011) argues, visual data raises ontological questions about the understanding of what is believed to be social reality. An example may concern the influence of visual media in the construction of individual or group identities and how imagery has the potential to distort in order to serve political and ideological ends. Epistemological concerns relate to

the way images are used to elicit knowledge about a particular subject, such as through shared codes (Spencer 2011). For example, the visual is expected to give evidence of existence, suggest reality and portray relative importance. However, although photographic images are 'true' in terms of the mechanical, chemical or electronic processes involved, the human eye and brain which composed the image and the complex mediated processes of interpretation make an image no more truthful than any other form of communication (Rose 2007, Spencer 2011).

As Becker (2004) states, there is, as yet, no clearly established methodological framework concerning the use of photographs in social science research. Mitchell (2011) suggests that it is often necessary to work across genres of methodologies concerning visual images when employing photography but says that reflexivity must be central and situating one's self in the research is critical to interpretation. Prosser (1996) argues that there has been little regard for visual research within a qualitative methodology that is dominated by language. He has called for a distinct and critical image-based methodology in order to enhance the status and acceptability of visual research within the wider research community, provide a platform to promote visual research and demonstrate how it can contribute positively and substantially to qualitative research and develop a framework within which the strengths, weaknesses and the potential of visual research can be debated. He outlines seven features and the arguments to support why these should constitute a visual methodology. These are reproduced in Table 3 overleaf.

Table 3: What constitutes a visual methodology? (after Prosser 1996)

Central features	Elements to consider
Words and images	• To remain credible images need the support of other forms of evidence such as narrative and research should not adopt an 'artistic' stance. • Consideration needs to be given to the manner and extent to which images are used and represented within a study. • Researchers need to decide where on the word/image (and journalistic/academic) continuum their study will be.
Frameworks and contexts	• Frameworks must be followed so that parameters of acceptable limits are maintained. (Within qualitative research there are a wide range of disciplines and perspectives to support research but the theoretical parallels found in film making or photo-journalism may be more helpful here, although possibly less easily translated to research). • The importance of context in the meaning and interpretation given to images should be a cornerstone of a visual methodology.
Data collection	• Accessing people, places and events, particularly with the intention of photographing them, should be carefully considered. Researchers should be explicit about the criteria and procedures informing their decisions.
Recording of data	• Cameras can record places, events or behaviours without tiring and allow the researcher to consider fine details at a more leisurely pace however data overload should be avoided.
Interpreting images	• A visual methodology must consider the way images are used and analysed and the quality of evidence they hold. • Contra to the 'visual' element of visual research, researchers must be aware that they 'perceive' rather than 'see' and therefore should provide a reflexive account of analysis.
Ethics	• Images are capable of carrying powerful and possibly sensitive messages, therefore ethical considerations and appropriate codes of practice should be agreed.
The research report	• There are few conventions and guidelines for academic articles and theses regarding the use of images, therefore researchers need to consider whether to conform as best they can to preset standards or "plough their own furrow" (Prosser 1996, p33).

Methodology and photo-interviewing

There has been a recent epistemological commitment within health and illness research to the way in which participants themselves interpret and make sense of their own experience (Harrison 2002[B]). These concern both 'everyday' events and those which disrupt and require new responses and a re-evaluation of identity (for examples see Bury 1982 and

Charmaz 1983). As I have explained above, inductive, qualitative, biographical research approaches are more suitable for investigating such phenomena and have appropriately dominated (Silverman 2000). Visual methods, either alone or in combination with verbal or written narrative, have also shown their potential here (van Leeuwen and Jewitt 2001, Harrison 2002[A], Spencer 2011). There has also been an accompanying and growing interest in the use of participant-produced visual methodologies, such as video-diaries, photo-interviewing and drawings (Guillemin and Drew 2010). However, the majority of visual methodologies outlined in the literature so far have involved the analysis of existing (or 'found') images or photographs produced by researchers and there has been little discussion about specific methodologies related to photo-interviewing (Prosser 1996, Rose 2007, Guillemin and Drew 2010). Wang (1999) and Wang and Burris (1997), when developing their original concepts of photovoice and photo novella, drew on action research methodology. Action research was originally designed to study social systems with an intention of modifying them and it emphasises organisational or community development by raising awareness then collaborating with, including and empowering all stakeholders to influence change (Bowling 1997). Guillemin and Drew (2010) stress that participatory visual methodologies are essentially 'enabling' to both researchers and participants but suggest that there are many theoretical issues that have not yet been addressed in photo-interviewing approaches and will not be until there is a much greater body of work to be drawn from and critical questions have been broached, discussed and satisfactorily resolved. They argue that this methodology requires as great a consideration of the process of image production as to the resulting images themselves.

How photo-interviewing may enable cancer-specific research

Some of the arguments that have been put forward to support photo-interviewing methods are that:

- Researchers may gain information that would be difficult to access by other methods

- The participant may secure more control in the research process

- Visual representation may offer a wider experience or understanding

I discuss these below drawing on the example of cancer-specific research to support the theoretical arguments.

Researchers may gain information that would be difficult to access by other methods

Photo-interviewing has the potential to allow researchers into environments they are usually excluded from and gain information that would be inaccessible by other means. Pink (2007) suggests that photographs can create important data about everyday experience and the personal space may be a prompt through which people can express their identity and experience. This may be important in the study of cancer survivors who are known to value a 'return to normality' (O'Baugh et al 2003, McCaughan et al 2010, Thomsen et al 2011). For example, photographs may allow them to take researchers and policy makers into their homes, gardens, work places, recreational and social spaces and other places where identity and roles are constructed (and disrupted). This is of particular importance when employing a symbolic interactionist approach which assumes that individuals' actions are dictated by the meanings attached to phenomenon that exist within their environment (Blumer 1969, Benzies and Allen 2001).

Photo-interviewing may also be important when the symptoms and side effects of treatment impact on peoples' physical ability to speak and therefore engage in interview based research, e.g. people who have had surgery to organs and tissues related to speech, people with dyspnoea, people with chemotherapy-induced stomatitis or pain and difficulty swallowing after radiotherapy to the head, neck and chest. Others may find it difficult to

verbally explain certain aspects of living with and after cancer simply because they find it difficult to 'put things into words', possibly due to emotional, psychological or semantic reasons (Kristiansen et al 2010). Photo-interviewing methods may offer a way of communicating for these people, therefore gaining a more comprehensive insight into the experience of cancer survival.

The participant may secure more control in the research process

Since the early 1990s, there has been a call for a more participatory approach to social science and health research. Participatory research was first developed within international development settings and was designed to reduce distrust, effect appropriate change and improve social conditions (Hall 1992, McCauley et al 1999) and organisations such as the National Cancer Research Institute have sought to encourage and advance it within cancer research since the early years of the twenty-first century (Hubbard et al 2008). Photo-interviewing has the potential to support this participatory approach because it literally places the data collection tool (camera) in the participant's hand (Harrison 2002[B]) and, as previously discussed, photovoice was designed specifically to empower disenfranchised or deprived populations (Wang and Burris 1997, Hurman 2003). Photographs also facilitate attention to be shifted if necessary, i.e. participants can choose to place themselves prominently, discretely or not at all within the frame of the photograph. In addition, giving people time to take photographs also allows them a period to capture the full nature of their experience. Unlike an interview which is usually booked to be at a certain time on a particular day, communicating with photographs means that, if participants are tired or find an aspect difficult to address one day, they may be able to attempt it on a subsequent day. This could be of particular relevance for people who are trying to manage disease symptoms and treatment side-effects.

Visual representation may offer a wider experience or understanding

Finally, the combination of both visual and verbal data has the potential to enable a more extensive and holistic understanding of a situation (Frith et al 2005). Photography may allow a sensory and emotive recreation of the participant's worlds thus creating a unique and specific understanding of a previously indescribable experience. This may be helpful when exploring 'new' phenomena brought about by, for example, increasing cancer survival, such as returning to work after treatment, forming new relationships with an altered appearance or living into old age with long-term treatment side-effects. Furthermore, it may permit people to communicate experiences or features that may otherwise be overlooked (Rapport et al 2005; Bagnoli 2009). For instance, cancer survivors may be unable to convey their complete experience because they are restricted by familiar words or phrases, whereas a more creative and interpretive approach may allow different aspects, perspectives and realities to be conveyed (Frith et al 2005; Bagnoli 2009). As Edwards has said, photography has the ability to "question, arouse curiosity, tell in different voices or see through different eyes" (Edwards 1997, p54).

Creating and interpreting photographs

There is a commonly held (mis)conception that the camera never lies (Sontag 1979, Baldwin et al 1999, Oliffe et al 2008). Photographs are often seen as automatically produced and therefore acquiescent to authenticity and able to somehow short-circuit the cultural constraints and intentions which are recognised to be present in other forms of representation (Lister 2003). However, photographs are created and viewed within particular social, political and historical contexts and are influenced by both the researcher and participant. As Oliffe et al (2008) explain, it is probably more precise to use the phrase 'a picture paints a thousand words'.

Symbolic interactionists argue that identity is constructed within relationships and interactions with others (Goffman 1959, Blumer 1969, Packard 2008). As such, all photographers will have their own creative vision (Rose 2007). What participants choose to include and exclude from photographs produced for photo-interviewing research become important factors in the 'reality' the image conveys (Berger 1972, Frith et al 2005). This may be a conscious act, such as 'setting a scene' or using software to alter a photograph or highlight a certain part of it, or less conscious, for example class, gender and ethnicity may influence the choice of visual image or the representation of self (Pink 1997; Wiles et al 2008). Drawing on examples of his own photo-interviewing studies with both hospital in-patients and homeless people, Radley (2010) argues that taking photographs involves more than just creating a visual display. More accurately, photographs provide a means of making sense of the participants' worlds and a means of communicating that to researchers or other members of an audience. As he describes:

> The photographs they made became sign vehicles for defining their location in those worlds and included ethical judgements as to 'how that world should be' (the response of medicine, the response of a housed society).

> Radley 2010, p278.

However, the person viewing the photograph will also have their own creative vision which will inform the meanings they give to photographs (Warren 2005, Pink 2007). A viewer will decode the features of a photograph through associations with their existing cultural references, experiences and interactions with others, although these are, in themselves, subjective (Spencer 2011). According to Barthes (2003), photographs have both an 'obvious' and 'obtuse' meaning (which he names 'studium' and 'punctum', respectively). The obvious meaning (in itself, culturally and contextually constrained) represents the commonly recognised elements in a photograph, whereas the obtuse meaning is often

personal and emotional and may disrupt the apparently unequivocal reading (Warren 2003, Spencer 2011). It is at the level of 'punctum' that photo-interviewing techniques operate and it is of particular importance to recognise this when analysing photographs produced for research employing these methods. As Becker (1974) explains, photographers exert enormous control over their images and the message they convey and their images are dependent on their own understanding of what they are looking at.

Analysis of photographs and interviews

Despite a history of analysing photographs and visual images within, for example, anthropology, cultural studies and psychoanalysis (van Leeuwen and Jewitt 2001, Spencer 2011), there has been little written to date about the qualitative analysis of photographs produced specifically for research (Rose 2007, Pink 2007). Some researchers have explicitly avoided formal analyses of participant-produced photographs for epistemological reasons, arguing that the photographer's interpretation has the most important, if not absolute, meaning (Oliffe et al 2008). Those who have discussed a method of analysis have usually based it on a 'grounded theory' approach, which emphasizes gaining understanding from phenomena that are grounded within the data itself and involves the constant comparison of this data with emerging categories to capitalize on the similarities and differences in information (Glaser and Strauss 1967; Strauss and Corbin 1990; Temple and McVittie 2005, Liebenberg et al 2012). This can be assisted by the growing number of computer-assisted qualitative data analysis software which can now accommodate visual data (Pink 2007).

Radley and Taylor (2003) and Rose (2007) recommend that researchers consider their analytical approach carefully so that photographs do not simply become illustrations of their accompanying interviews. One of the few analytical frameworks that have been outlined for participant produced photographs is known as 'layered analysis' (Dowdall and

Golden 1989, Oliffe et al 2008). Layered analysis was originally developed by Dowdall and Golden (1989) as a tool in which to examine a historical collection of photographs depicting life in a large mental hospital [sic] in the United States. Their initial approach consisted of three stages:

1. Appraisal - the individual photographs were viewed to see how the hospital presented itself and its patients

2. Inquiry - the whole photographic collection was examined for emerging themes

3. Interpretation - individual photographs were probed to explain phenomena that had emerged.

This approach has been adapted by Oliffe et al (2008) to analyse the participant-produced photographs and associated interview data they collected for their ethnographic study about new fathers and their perspectives on their own smoking habits.

What do people take photographs of?

Corresponding to Cooley's concept of the 'looking glass self' as described in his work on symbolic interaction, here are certain conventions involved that define personal or amateur photographs (Cooley 1902, Van Dijck 2008, Pink 2011, Van House 2011). These should be recognised when involving participants in a photo-interviewing study as they may have the potential to influence the photographs created. For example, Guillemin and Drew (2010) describe a young participant who talked about the physical, emotional and isolating struggle of living with chronic fatigue syndrome but only produced what they call 'happy snaps' of herself dressed up for social outings and special occasions. It has been recognised that dominant subjects for personal photographers are family and friends and, to a lesser extent, tourism (Sontag 1979, Van House 2011). This has been replicated in photo-interviewing studies which have been analysed quantitatively by content

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(Einarsdottir 2005, Lassetter et al 2007). For example, 78% of the photographs taken by the siblings of children with Down's Syndrome in Rampton et al's (2007) study were of people and 85% of these were of family members. Similarly, over half of the photographs produced for Lassetter et al's (2007) study with parents of children with disabilities were of families involved in seemingly enjoyable activities. Such photographs then become both a memory tool and a way of communicating and sharing experience (Van Dijk 2008). Van House (2011) categorises personal photographs into four related 'uses': personal or group memory, relationship creating or maintenance, self-representation and self-expression and explains:

> Who is in a photograph, when a photograph is taken, who it is shared with and how, the stories that are told around it, all these have traditionally been important to relationships.
>
> Van House 2011, p130.

It is also important to note that photography and the sharing of images is changing with technological innovation, market forces and sociological and cultural changes. Van Dijk (2008) argues that, particularly since the turn of the century and allied with cultural shifts involving individuality, communication and distribution, cameras are becoming tools to converse, communicate everyday experience and foster peer groups. As such, there may be differences in the subjects, representation and purpose of photographs produced by different ages of participants involved in a photo-interviewing study.

Legal and ethical issues in photo-interviewing

Due to its relative newness, visual research and photo-interviewing lack a history of ethical practice. Ethical issues are frequently omitted from research articles and reports and there is little consensus amongst both ethics committees and visual researchers themselves

about standard practice and acceptable guidelines. This is complicated further by the rapid growth in practice and technology, heterogeneity of application and the complexity of image creation, dissemination and consumption (Prosser 2003, Pink 2007, Prosser and Loxley 2008, Prosser et al 2008). Prosser and colleagues stress that ethical issues are often related to the specific contexts of individual studies making guidance about good ethical practice "contested, contextual and dynamic" (Prosser et al 2008, p3). Furthermore, they say that decisions should not be made in isolation but be informed by an understanding of and engagement with ethical theory and in the context of a framework that accommodates the researcher's moral outlook as well as professional guidelines. Different research ethical issues may emerge depending on who takes a photograph and for what purpose it is taken (Wiles et al 2008). Here I will focus on those that may occur when research participants produce their own images, for example for photo-interviewing studies, as these are pertinent to my work and I will discuss them in relation to the four factors that influence ethical issues and decision-making for visual researchers:

- law and copyright

- ethics committees and review boards

- confidentiality and anonymity

- the researcher's own moral framework.

Law and copyright

A number of legal considerations concern visual research and photo-interviewing, mainly related to the creation of photographic images and ownership (Wiles et al 2008). There are no laws restricting photography in public places in the UK and no group of people who are categorically "off-limits" (Henderson in Wells 2003, p279). However, there may be situations in which the creation of photographs may impinge on public order or privacy legislation, lead to obstruction, provoke a tense situation, be considered harassment or risk

security, all of which may have legal restrictions and consequences. Furthermore, photographing someone in a place in which they would expect a reasonable amount of privacy may be considered an invasion of that privacy and contravene the European Convention on Human Rights (McPherson 2009). There may also be complications in defining a 'public space'. For example, managers may dispute that their shopping centre, hospital or library is a suitable public space for the purposes of photographic data collection (Wiles et al 2008). Ownership of photographic images produced for photo-interviewing is determined by copyright law. In the UK, a photograph is considered to be an 'artistic work' and, as such, may be copyrighted. The photographer is then the holder of the copyright and a researcher may only use that image if given explicit permission to do so by the photographer/participant (Wiles et al 2008, Prosser et al 2008). Finally, all researchers are subject to the Data Protection Act which demands that data is kept securely allowing for no breach of confidentiality. However, provided consent has been obtained for the use of the photographs, no additional protection appears to be needed for visual data compared to more traditional research data (Wiles et al 2008).

Ethics Committees and Review Boards

As Prosser et al (2008) explain, the law provides a lowest common denominator and, just because something is legal, does not guarantee that it is ethical or moral. In order to steer researchers through ethical dilemmas they may encounter and protect and re-assure both them and participants, many professional guidelines and codes of practice have been created (Wiles et al 2008). Within health and social care these largely stem from the 1964 Declaration of Helsinki which detailed a set of ethical principles drawn up by the World Medical Association and in response to the horrifying experiments performed on prisoners of war made public at the 'Doctors' Trial' during the Nuremburg Trials in 1947. These frameworks generally relate to the well-being, dignity and rights of participants, issues of

informed consent, balancing the needs of the individual and society and principles of privacy, confidentiality and anonymity (Wiles et al 2008).

Ethics committees (in the UK) and review boards (in the USA) provide a regulated system of independent review to oversee research on and with humans. Although ethics committees' principles are standard, their conclusions can vary widely. For example, Frith and Harcourt had no opposition in their study proposal of women taking photographs of their breast cancer chemotherapy experience, whereas Radley and Taylor were refused permission to allow their participants to take any photos of people at all (Frith and Harcourt 2007, Radley and Taylor 2003). This may have been due to Radley and Taylor's participants being hospital in-patients as opposed to Frith and Harcourt's who took photos outside the hospital setting, although any implications regarding confidentiality, well-being and consent on people photographed for the two studies would arguably have been the same (personnel communication with the authors). There has been criticism of the limitations that this inconsistency may place on social research (Murphy and Dingwall 2007, Wiles et al 2008). Prosser et al (2008, p11) explain that visual methods may be further limited because ethics committee members are likely to be more familiar with words-based and number-based research and may therefore find image-based research proposals difficult to interpret. They call for 'proactive practitioners' to educate, debate and contribute to ethical committee functioning and this is beginning to be addressed by, for example, Visualsociology.org.uk (The Visual Sociology Study Group of the British Sociological Association) who have published a Statement of Ethical practice (British Sociological Association 2006).

Confidentiality and anonymity

Confidentiality and anonymity are central principles of ethical research (Harrison 2002[B], Crow and Wiles 2008). However, visual methods are often employed because images can reveal more than text alone and because they hand control to the participants and communities (Wang and Burris 1997, Harrison 2002[B], Wiles et al 2008). As such, it may be impractical or even impossible to maintain the anonymity of a subject in a photograph or other visual image and research in relation to text based methods show that participants are often keen to be identified in research (Grinyer 2002, Guillemin and Drew 2010). This is further complicated when individuals wish to be identified, for example, when participants are disabled and have argued for their right to be visible (Wiles et al 2008). As Prosser et al (2008) suggest,

> If an aim of (particularly participatory) visual research is to empower and give voice to marginalised groups and individuals but those individuals and groups are anonymised against their wishes, this raises important questions about power relationships in research and control of the research.
>
> Prosser et al 2008, p15.

As previously discussed, photographs of people are common in studies employing visual methods (Sontag 1979, Rampton et al 2007, Van House 2011). Methods of obscuring identity may be employed, such as the pixilation of facial features in order to blur them, the use of specific anonymisation software that converts images into cartoons or drawn images and the blocking out of eyes, faces or other distinguishing features (Wiles et al 2008). However, obscuring facial features may not make an image completely anonymous. Subjects may be recognised by the environment they are photographed in, their gait, a tattoo or a pet photographed with them (Prosser et al 2008). Although Radley and Taylor's (2003) participants were disallowed to photograph individuals by an ethics committee, they

did effectively place the individuals into the images by talking about them in relation to the objects and places in the photographs. Obscuring facial features is also a contentious practice and has been criticised by some social researchers who have questioned whether 'sanitising' images impacts on the integrity of the data (Wiles et al 2008). Wiles and her colleagues (2008) discuss how obscuring features affects the interpretation of visual images because faces may explain physical, psychological, social and emotional aspects of individuals. They also argue that blurring or obscuring faces objectifies people and removes their identity. They say, "without faces people appear not as people at all but as objects, this does not accord with a duty to treat people with respect" (Wiles et al 2008).

Oliffe and Bortorff (2007) make an important point concerning their research with men who produced photographs depicting their prostate cancer experience. They argue that the ethical considerations surrounding non-visual research may actually be greater than those they had to consider because their participants held the exclusive rights to what images were taken, seen and shared. If they had agreed to interviews and observation, this control would have been virtually impossible.

The researcher's own moral framework

Prosser et al (2008) discuss how, in attempting to classify and build a framework of visual ethics, there is a danger of losing sight of the fact that it is individuals who make ethical and moral decisions. They say,

> There is significant accord in terms of a collective moral compass yet substantial disagreement about the application of ethical principles to particular research contexts. Bridging the gap between shared principles and individual's practice is imperative if visual research in the future is to flourish.

> Prosser et al 2008.

They explain the three broad approaches to research ethics, namely consequentialist, non-consequentialist and ethics of care. Consequentialist approaches maintain that ethical decisions should be based on the consequences of specific actions so that an action is morally right if it will produce the greatest balance of good over evil. Non-consequentionalist approaches claim that ethical decisions should be based on notions of what it is morally right to do regardless of the consequences or research ends. Such value terms are often found in ethical guidelines and ethical advice from professional bodies and form the basis for evaluating applications to ethics committees. In an ethics of care approach, decisions are made on the basis of a desire to act in ways that benefit the individual or group who are the focus of research. Prosser and colleagues (2008) argue that this is not widespread within orthodox research but that an ethics of care approach is often adopted by those pursuing collaborative and participatory methods including visual research. They suggest that ethical gaps and anomalies occur when ethics committees apply non-consequentionalist values and attempt to prioritise ethical principles to different contexts. Pink (2007) claims that ethics in such research refers to far more than just the conduct of the researcher; it also demands an understanding of the ethical context or contexts in which the research takes place, reflexivity from the researcher about their own beliefs and a critical approach to ethical codes of conduct and any hierarchy that exists between them.

Dissemination of participant-produced photographs

Visual research, possibly more than other methods, can be disseminated in a number of ways, such as via exhibitions (e.g. Fleming et al 2009), books and publications (e.g. Alsop et al 2006), digital media (such as the internet) as well as conventional means such as conference presentations or journal articles. The mode of dissemination presents different

ethical implications in relation to anonymisation and identification which should be considered carefully and discussed with participants (Prosser et al 2008). For example, the internet offers significant opportunities for global dissemination but, without restricting access to sites, may allow images to be copied and reproduced out of the context in which they were obtained (Pink 2007).

Pink (2007) advocates a collaborative approach in selecting photographs for dissemination but recognizes that the final decision may have to rest with the researcher and/or editor. She therefore suggests that the final representation should not simply reflect the willingness of participants to allow their photos to be published but should also take account of the social and cultural contexts in which the images will be viewed and interpreted and researchers should be aware that published images may have political implications.

Conclusion

Despite the significance of vision in contemporary culture, the application of visual methodology and the use of visual methods, such as photo-interviewing, remain a relatively new and developing approach to research into health and illness. Potentially they have the ability to benefit both researchers and participants. Researchers may obtain more rich, holistic, profound and multifaceted data from a greater population base. Participants may be more empowered within the process, more able to take part in research and more able to effectively explain their experience. However, the relative originality of such methods means that certain processes and considerations are not thoroughly tried and tested as yet. For example, formal methods of analysis remain in their infancy and there is still much debate about ethics and the confidentiality of visual data. Furthermore,

philosophical and contextual issues about the creation and consumption of images need to be addressed when employing photo-interviewing techniques in research.

In spite of these uncertainties, I was encouraged by the arguments in favour of visual methods and chose to employ them in my feasibility and principal studies, which are discussed in the following chapters of this thesis.

Chapter 5

Feasibility study: Methods and process

Introduction

In this chapter, I describe my feasibility study which was intended to test the method of requesting people with head and neck cancer to create photographs to illustrate and explore their experience of living with cancer. I explain how it came about and the processes I followed. The study did not go to plan, in particular because recruitment was very poor. I therefore describe the difficulties I faced and what I did to address them.

Background

As discussed earlier in this thesis, my philosophical position is interpretivistic and is focused in the way the world is experienced, understood and interpreted. I work within a symbolic interactionist framework and believe that people are creative, rather than simply responsive, agents in their social world and it is important to recognise how they operate within a society, the meanings they give to experiences and, therefore, how people construct their own reality and sense of self (Cooley 1902, Mead 1934, Charmaz 1983, Mason 1996, Bowling 1997).

I have been a nurse for all of my working life and for most of that I have worked with people who have cancer. I realise that the word 'cancer' has connotations way beyond its name, making it somehow *more* than a disease. Sontag (1991) and Stacey (1997) have eloquently written about how its cultural perception affected their own experiences of having cancer and I have observed the profound affect that being given a diagnosis of cancer can sometimes have on an individual and the people close to him or her. This is despite it becoming an increasingly common and chronic disease with a better prognosis

than some other diseases such as heart disease and Alzheimer's disease (Stewart et al 2001, Larson et al 2004, Macmillan Cancer Support 2011).

Furthermore, throughout my career, I have tended to work with people with ovarian and lung cancer. These are cancers with a poorer prognosis i.e. 34% and 6% likely survival at five years respectively (Cancer Research UK 2009[A]). Cancer survival rates are increasing significantly overall, with median survival rising from one to nearly six years between 1972 and 2007 (Macmillan Cancer Support 2011), leading to what King has called "the culture of survivorship" (King 2006, p101), in which an "ideal model of survivorship" (King 2006, p104) has been circulated and 'survivors' are celebrated. However, the non-specific term 'cancer' applies to over two hundred different pathological 'types' and there has been little improvement for some. For instance, median survival for stomach, oesophagus, pancreas, brain and lung cancers remains at less than a year (Macmillan Cancer Support 2011). I question whether this adds a further assault to those diagnosed with a less survivable cancer. As Ehrenreich (2001) suggests, does the conceit of survivorship denigrate those who are more likely to die of their disease?

Development of the feasibility study

When I started studying for my PhD, I was working as a full-time clinical trial co-ordinator for a national head and neck cancer study. Through discussion and research planning with colleagues and literature searching relevant to my job, I was made aware that much of the information about the disease and treatment burden of head and neck cancer (HNC) has been derived from validated 'quality of life' (QOL) questionnaires designed to systematically assess health, wellbeing and outcomes (Mathieson and Stam 1995, Rogers et al 2007, Semple et al 2008). Such quality of life measures are standard in so called psychosocial research, easy to administer and have offered valuable information that has

contributed to the current focus of care for people with HNC. For example, they have

highlighted the high incidence of pain after treatment (Epstein 1999) and identified specific

predictors of QOL, such as a lower QOL if a feeding tube is necessary or a co-morbid

condition is present (Terrell et al 2004). However, QOL questionnaires often focus on the

performance of activities and role functioning (Albrecht 2005) and are based on the

assumption that social phenomena in relation to illness and health are measurable

(Bowling 2007). It has been argued that such numerical tools may miss domains that are

pertinent to some respondents and are unable to capture the spectrum of subjective

experience and interpretation (Koller et al 2005, Bowling 2007). According to Mathieson

and Stam (1995), they are adapted from biomedical assumptions and are an attempt to

classify people according to their emotional or physical response to cancer and their ability

to adjust 'successfully' or not. They therefore suggest that a narrative approach would be

more appropriate to use when exploring living with cancer biographically which does not

superimpose a professional model on individuals' experiences and rejects the concept of

individuals 'managing' their cancer experience. For these reasons, I also argued for the

inclusion of more interpretive approaches in the programme of research but soon became

aware that a large proportion of people with HNC may be excluded from research

employing qualitative methods, simply because HNC treatment or the disease process itself

can cause temporary or permanent speech loss or significant speech impairment in up to a

third of these patients (Rodriguez and VanCott 2005) and so they are unable to take part in

the usual data collection method of verbal interviewing (Holstein and Gubrium 1997,

Mason 1996). For example, Semple and colleagues' qualitative study about the lifestyle

changes experienced by people after HNC treatment and Larsson and colleagues' study on

eating problems during HNC radiotherapy both relied totally on semi-structured interviews

(Larsson et al 2003, Semple et al 2008). People with communication problems have been

classified as one of four 'seldom heard' groups by the Social Care institute for Excellence

(2008). Although the importance of their inclusion in research and service development has been stressed, I was unable to find any published work that included people with verbal impairments following HNC in research employing qualitative methods.

While studying for my Master's degree, my work focused on the impact of media reporting about cancer for people living with the disease (Balmer 2005). From this interest in the representation of cancer generally, I have become more interested in the visual representation of health and illness specifically and subsequently the possibility of employing visual methods in research as a relevant alternative to allow people with communication difficulties to convey their experience.

I discussed my ideas with a colleague (head and neck cancer surgical consultant) who agreed to support me and I began to prepare a feasibility study to investigate whether visual methods had the potential to explore issues concerned with living with and beyond cancer for people diagnosed with HNC and with resultant communication difficulties.

Head and neck cancer: what is it?

Head and neck cancer is a heterogeneous group of cancers that can affect more than thirty different sites (National Institute for Clinical Excellence [NICE] 2004). There are approximately 6,700 new cases of HNC each year in England and Wales. About 90% of these cancers are squamous cell cancers and the majority arise from the mouth, lip and tongue (oral cavity) and the voice box (larynx) (DAHNO 2008). It is predominantly a disease of men over forty and is often related to lifestyle or environmental factors. The primary risk factors are smoking, chewing tobacco and alcohol use. Alcohol both potentiates the effects of smoking as well as being a separate risk factor. A poor diet is also an associated factor, although this may be related to a high alcohol intake and tobacco use. Viral infection, in

particular with Human Papillomavirus (HPV), also appears to lead to lead to a greater risk, especially of oropharyngeal cancer (NICE 2004, Döbrõssy 2005).

There are marked regional variations in the incidence of HNCs, both globally and nationally. For example, in the UK rates range from 8 per 100,000 in the Thames and Oxford regions to 13-15 per 100,000 in Wales and the North West. Smoking related HNCs are more than twice as common amongst men from the most deprived social groups (NICE 2004, Hassan et al 2006). In Central and Eastern Europe, there has been up to a tenfold increase in incidence in one generation, linked to increased alcohol consumption (Döbrõssy 2005).

Despite improved treatments and reconstructive techniques, survival in HNC is poor (e.g. the five-year survival following a diagnosis of laryngeal cancer is approximately 50%) and is often linked to lifestyle, older age of incidence, co-morbidity, deprivation and late presentation (Paterson et al 2002, NICE 2004, DAHNO 2008). Seven or eight deaths per day in the UK are attributed to head and neck cancer (Llewellyn et al 2006). Furthermore, the disease burden for people with HNC is significant. Patients often require intensive investigations, multiple treatments over a long period of time and prolonged rehabilitation. The disease and its treatment impact on eating and drinking, speech, smell, sight, breathing and appearance, which may profoundly affect social interaction, emotional well-being and role function including work (Paterson et al 2002, Ziegler et al 2004, Murphy et al 2007, DAHNO 2008).

Study aims

The aim of the feasibility study was to investigate the acceptability, practicability and relevance of using a visual method (participant-produced photography) as a method of data capture to explore the experience of living 'with and beyond cancer' (Macmillan

Cancer Support 2008[A and B]) from the perspective of people whose ability to communicate verbally has been seriously affected by head and neck cancer and its treatment.

Choice of method

There are many types of participant produced visual data including photography, drawing, sculpture, video, dance or theatrical performance (Pink 2007, Prosser and Loxley 2008, Bagnoli 2009). However, one of the basic tenets of this research study was inclusion and I wanted to choose a visual method that would be as familiar, easy to use and non-threatening to execute to the most number of people. As Wood (2005) explains, unless they are already familiar with art and artistic media, art materials can be daunting for people with cancer and Falk (2005, p174) talks of "performance fear" in art making. Furthermore, I had no funding for extensive training for either myself or the study participants or for the purchase of expensive equipment, such as video cameras. The method needed to be as pragmatic, economical and comprehensive as possible. Thus, I chose participant-produced photographs.

Photography is the method of visual participatory research that has received the most attention (Mitchell 2011). Sontag, writing in 1977, argued that photography was widely practised by many people and recent rapid advances in digital technology have made the production, exchange and display of photographs even more common, widespread and open to all (Sontag 1979, Mizen and Wolkowitz 2006). Importantly, photography is a pastime of mine and, after seeking out and attending a couple of relevant training courses, I felt confident enough to discuss and advise participants about photographic production.

Visual methods using participant-produced photographs, usually known as 'photovoice' (e.g. Wang and Burris 1997) or 'photo elicitation' (e.g. Frith and Harcourt 2007), have

tended to be used to prompt and generate narrative (see chapter 4 for details). It was recognised that for people left 'voiceless' after head and neck cancer treatment, photographic data may have been the only significant source of data rather than a trigger and adjunct to interviews. However, participant produced photographs have been used to explain concepts that are difficult to articulate verbally, such as pain (Bendelow 1993) and, as photography has been described as a "data collection method that gets around the problem of verbal and written communication" (Nind 2008, p13), I felt it would be worthwhile to test the method. Although I did not want to insist upon it in case it excluded people who would find it difficult or certain topic areas, I intended to encourage participants to supplement photographs with written data explaining the photograph and why it was taken. I also envisaged that triangulation with observations made about the way participants organised, chose and displayed their photos would also help to validate and enhance any data produced.

I purchased five basic digital cameras that could be lent to people who did not have their own and a photo printer that could be taken into participants homes (or the venue at which they wished to display their photographs) so that copies of photographs could printed if they did not have the ability or technology required to transfer them.

Study support

Hospital staff

The consultant surgeon (surgeon one) I was working with at the time agreed to support the study and identify potential participants for me from his clinic at the University Hospital Coventry and Warwickshire (UHCW). He suggested I seek the help of another consultant surgeon at a neighbouring hospital; the Queen Elizabeth Hospital at University Hospitals Birmingham (UHB). I arranged a meeting and this surgeon (surgeon two) also agreed to

identify potential participants for me. I also identified and spoke to HNC speech and language therapists (SALTs), research nurses and HNC clinical nurse specialists at both hospitals who all agreed to identify potential participants.

User involvement

Service user involvement in health research emerged during the 1980s and organisations such as the National Cancer Research Institute have sought to support and advance it within cancer research since the early 2000s (Brown et al 2006). Although there have been criticisms of it, for example in the representativeness of those who volunteer to become involved (Wright et al 2007), I was keen to seek the advice of users, especially as the method was novel. Following advice from colleagues who had existing links with previous users involved in HNC research, I formed a small study user group consisting of:

1. A former patient with permanently altered speech following treatment for HNC and a member of the National Cancer Research Network Consumer Liaison Group

2. The wife and carer of a former patient with HNC and founder member and secretary of the Sunderland Laryngectomee Support Group from which she had gained a huge insight into the problems of people who have altered or no speech following HNC

3. A former patient with oesophageal cancer and Chair of The Oesophageal Patients Association. Although having had a different cancer, this gentleman had experienced similar treatment side-effects.

The study user group members were asked to review and comment on the study design and protocol. In particular they were asked whether they thought the method was practical and whether the participant information leaflet and associated patient literature was suitable. All expressed their support of the study and felt that useful data would be

produced by photography and that it was a method that all patients could utilize. A couple of changes were suggested and incorporated into the patient information leaflet.

Ethical approval

The protocol was approved by the Coventry Research Ethics Committee in November 2009 and given NHS Research Governance approval by UHCW in February 2010 and UHB in March 2010.

Planned study process

Sample size

It was envisaged that five participants would be enough for the feasibility study to determine whether the method was successful. If five participants were able to produce photographs that could communicate aspects of experience, it was planned that the study would be extended to one which had the aim of producing meaningful data about living with and beyond HNC for people left with communication difficulties.

Inclusion criteria

The inclusion criteria were:

- Patients with histologically or cytologically proven head and neck small cell carcinoma (or occult carcinoma which was to be treated as such)

- Patients who had completed treatment

- Patients who had had treatment for HNC which had left them with no voice or a significant speech impairment (e.g. an inability to make themselves understood verbally to strangers) *or* patients who had difficulty speaking about some or all of their HNC experience due to emotional and/or psychological reasons

- Adult patients (age≥18 years)

- Patients able and willing to give informed consent to participate in the study

- Patients able to understand English.

Patient identification and enrolment

It was planned that patients who met the inclusion criteria would be given a study pack by the staff who had agreed to identify them. The pack comprised an invitation to join the study, a patient information leaflet, a reply slip on which potential participants could indicate whether they were interested in participating and supply contact details and a stamped addressed envelope (SAE), addressed to myself. I distributed fifty packs in total to consultant one, consultant two and each SALT and research nurse team and I also supplied study reminders to pin to clinic notice boards. My plan was to contact all potential participants who returned their contact details via the SAE, discuss the study in greater detail with them via their preferred means (i.e. possibly via an intermediary or in writing if verbal communication was extremely limited) and organise a mutually convenient first meeting. At this meeting, if they were happy to take part, patients would give written consent.

Study procedures

Consenting participants were to be advised about recognition in photos (this is discussed in more detail in chapters four and seven) and requested to take up to twenty photographs of anything that represented and signified 'living with and beyond head and neck cancer' for them.

I intended to contact participants (and/or carers) in a way that suited them (e.g. via telephone or e-mail) after recruitment to ensure they were having no problems with using the camera, the photography process or choosing themes/subjects to photograph.

A data collection and analysis visit was to take place approximately two weeks after recruitment. A photo printer would be taken to this visit and the subjects would be asked to choose, print and display approximately five to ten photographs that they had taken. Field notes were to be taken to record incidents, non-verbal communication and reactions that occurred during the data collection and analysis session. Although participants were to be advised that the photographs they chose to print would all be used for analysis, a Photo Reproduction Permission Form was prepared for them to give written consent for the reproduction of all, some or none of their photographs for educative and non-commercial presentations and publications of the research study and results.

Data analysis

For this feasibility study, data analysis was to focus on the following:

- Is data actually produced by this method of data collection?

- Are the photographs of sufficient quality for use as data?

- Are participants able to convey experience and meaning through this method?

What actually happened: Patient identification and enrolment

The study opened at UHCW and UHB in early Spring 2009. After about three weeks, I had received no returned SAEs, so I contacted the consultant, SALT and nurse teams to ask them whether they had seen any potential participants. Although some packs had been distributed, they had been so at inappropriate times (e.g. straight after surgery) or in inappropriate ways (e.g. sent 'cold' to potential participants through the post). I therefore reiterated to staff how I would like them to be distributed to maximise recruitment. Consultant 2 asked if I would attend his follow up clinics so that I would be there to speak to any potential participants he saw immediately, which I started to do from late March.

This also gave me an opportunity to catch up with the consultant and SALT team weekly to remind them about the study.

However, I still did not receive any referrals. I asked consultant 1 if he would like me to be available at his follow-up clinics too so that I could speak to any potential participants that he saw. He agreed and so I began to attend clinics – and remind staff - once a week at UHCW also.

In April, I arranged formal meetings with the teams at UHB and UHCW to review the study. The team at UHB said they had sent out a total of seven packs to people they felt would be potential participants. The team at UHCW said they had identified two participants but one was not approached as their disease had progressed and one had said he/she was not interested. Another pack had been given to somebody who was still recovering in hospital after their initial surgery. I also spoke at a HNC Patient Support Group meeting, managed by the HNC clinical nurse specialist at UHCW. This generated a lot of interest and discussion amongst the attendees and four information packs were taken at the end of the meeting.

I continued to attend the weekly follow-up clinics at UHB and UHCW and ask for regular feedback from all the staff members until the end of June 2009. Eventually twenty three potential participants had been identified to my knowledge, as illustrated in table four overleaf: 'Identified potential participants for feasibility study and outcome' (p147), plus an extra four who had identified themselves at the HNC Support Group Meeting. I personally spoke to six potential participants at UHCW follow-up clinics, two of whom enrolled into the study. A further eleven were given information packs and/or explanations about the study by HNC team members at the two hospitals but none of these potential participants referred themselves. None of the four who took information away after the Support Group

returned a contact slip. Another six identified patients were not approached because they had disease progression confirmed at the follow-up appointments at which I had planned to approach them about the study.

Table 4: Identified potential participants for feasibility study and outcome

Potential participant number(s)	Identified by:	Information received from:	Outcome	Explanation (if available)
1-7	SALT team, UHB	Info packs only	No returns	
8-10	Registrar, UHCW	Info packs & registrar	No returns	
11	SALT team, UHCW	No info given		Detection of disease progression at follow-up appointment
12	SALT team, UHCW	Info pack & SALT	No return	Patient not interested in the study
13-17	Consultant 1, UHCW	No info given		Detection of disease progressions at follow-up appointment
18	Consultant 1, UHCW	Myself		Patient not interested in research
19	Consultant 1, UHCW	Myself		Patient considered he had too many other things to think about (significant co-morbidities)
20	Consultant 1, UHCW	Myself		Patient did not want to take part as there was no personal gain
21	Consultant 1, UHCW	Myself		Patient's wife considered it too early after surgery to take part
22	Consultant 1, UHCW	Info pack & myself	Consent given	
23	HNC Nurse specialist, UHCW	Info pack & myself	Consent given	
24-27	Self-identification (UHCW Support Group attendees)	Info pack & myself	No returns	

After more than four months, I had only successfully recruited two participants. By then I was keen to learn from this study and start to plan one that was likely to be more successful, so I stopped attending the clinics but asked staff if they would still look out for possible participants and let me know if they handed out any more information packs or

had any patients they'd like me to speak to. Unfortunately, I received no further referrals or reply slips. After another two months, in August 2009, I closed the study to further recruitment.

Poor recruitment

Recruitment was far more difficult and protracted than expected. Patient confidentiality and the Data Sharing Code of Practice (Information Commissioner's Office 2011) made it impossible for me to know categorically why some of the identified potential participants I did not speak to personally decided not to present for possible recruitment to the study. However, using the limited data I have from the patients who chose not to take part and the available literature, I discuss some possible reasons below:

The patient group

Although the problems associated with poor and slow recruitment have been highlighted in the literature and suggestions have been made about why this may be so, there is very little published work that has investigated patients' own reasons for non-participation in research (Ross et al 1999, Cox and McGarry 2003). Furthermore, existing literature tends to focus on barriers to clinical trial rather than qualitative research (Dyas et al 2009). However, as mentioned previously, it is acknowledged that the functional, psychological and social disease burden associated with a HNC diagnosis and treatment is very large (Ziegler et al 2004). The disease and exhaustive multimodality treatments that are often required significantly affect eating and drinking, speech, smell and breathing which have a major impact on social interaction, work capabilities and role function which can worsen over time (Ziegler et al 2004, DAHNO 2008). Furthermore, co-morbities are common (DAHNO 2008). It is recognised that people who are more 'unwell' and have a greater psychological response to their illness are less able or willing to give consent to research

involvement (Taylor 1999). Schaffer et al (1996) found that the severity of illness had an impact on the ability of research participants to retain information about the study to which they had consented and their understanding of its purpose. Furthermore, in a study by Gysels et al (2008), people with cancer were more likely to refuse entry into a qualitative study than other people with serious, life-shortening illness due to having other priorities and the perception of the distress of diagnosis. Although I used self-referral to try and maintain the confidentiality of all patients and prevent anyone feeling compelled to take part, I recognise that this may have been a very proactive recruitment procedure for some people who had more immediate disease-related concerns. This was corroborated by two identified patients I spoke to; one of whom had significant breathing difficulties and cardiac problems on top of his HNC and who felt taking part would be too difficult for him and the other whose wife felt it was too soon after his HNC surgery for him to consider.

HNC is also associated with high mortality (DAHNO 2008). This was made evident by the high attrition rate between identifying and approaching patients. Six of the twenty seven identified patients were known to have disease progression detected between these timepoints and this rate may have been higher if it occurred in the group who were sent information packs or the support group attendees who took information packs away.

HNC is also more common in men, older people and people living with more social deprivation (DAHNO 2008) and is slightly more prevalent in South Asian ethnic groups (National Cancer Intelligence Network and Cancer Research UK 2009[A]); these are all factors which are known to adversely affect research response rates (Patel et al 2003, Lewis et al 2003, Hussain-Gambles et al 2004).

Medical, nursing and allied health professional factors

'Lasagna's Law' describes the phenomenon that the number of suitable patients for a study decreases sharply as soon as a study opens but returns to its original level as soon as the study closes (Torgerson et al 2001, Gul and Ali 2010). Bearing this in mind, I was less optimistic than the hospital staff I spoke to about the likely speed of recruiting patients. However, a randomised controlled trial managed from Warwick Medical School with more narrow inclusion criteria (PET-Neck) was managing to recruit at least one patient per month from each site at the time and so I was disappointed that consultant two was unable to identify any potential participants. I was aware of some of the barriers to clinical participation, such as lack of staff, lack of time and difficulty with consent procedures (Ross et all 1999, Cox and McGarry 2003) and had tried to prospectively manage these by producing comprehensive information packs and asking potential participants to contact me rather than hospital staff. However, other recognised barriers, such as concern for patient welfare and disinterest in the study question (Ross et al 1999, Cox and McGarry 2003) were less easy to control for. Dyas et al (2009) warn that an expressed interest in a study and willingness to sign up (especially if the researcher is known to the clinician) does not necessarily translate into motivation to recruit. Joseph and Dohan's (2009) ethnographic study of recruitment by clinical investigators, found that physicians and nurses used a complex, subjective and flexible process to identify and target who they thought would be 'good study patients' who were usually perceived as meticulous, proactive, compliant people who could communicate well with staff and who had strong support networks. They ask whether formally accepted 'patient barriers' to recruitment may actually be formed by the perceptions of clinical staff and impede their willingness to offer study enrolment. In a patient group with a high incidence of social deprivation, anxiety and/or depression and long-term functional problems (Whale 1998, Paterson et al 2002) these perceptions may have been exacerbated.

Environment

I was asking participants to be identified in therapeutic environments, however the focus for staff in these environments is on surveillance, treatment and rehabilitation and the only studies that they were used to recruiting to were clinical trials. As such, I could not expect my study to be prioritised and think it is likely that information giving about therapeutic trials took precedence over the distribution of my information packs. Furthermore, communication and method of study presentation is regarded as a key component of decision making regarding recruitment for patients (Taylor 1999, Cox and McGarry 2003). I chose to compile information packs for reasons of confidentiality for patients and ease of distribution for staff, however, this meant I was not always present when the information was delivered and was sometimes unavailable to explain the unusual research method. This may have affected recruitment because the only two participants who were eventually recruited were two I managed to speak to directly. Patel et al (2003) advocate 'tracking' non-responders two or three times to optimize recruitment. This may have been successful as some patients may have received posted information packs when other life events were taking precedence and at least three patients at UHCW received information immediately after surgery. However, due to the deliberately confidential nature of the information packs, this was not possible.

Method

Although there has been a growing interest in visual research methods over the last couple of decades, they remain a very novel way of doing research (Prosser and Loxley 2008). Catalani and Minkler's (2009) comprehensive review of published photovoice projects before 2008, calculated that only 1006 participants had ever engaged in such research at that point. I was unable to find any useful information in the literature about engaging and recruiting potential participants for photography-based studies specifically but Kearney and

Hyle (2004) describe the negativity and apprehension that their participants expressed when asked to produce drawings to represent the emotional impact of change for them. As Patel et al (2003) advise, few patients are likely to take part in research unless they can understand it and identify with its relevance. Without any personal contact to explain the study verbally, it was a lot to ask patients to engage in a method that must have seemed strange and perhaps inconsequential to them.

Encouragingly, of the few patients who gave a reason for not wishing to take part, all stated individual reasons associated with their ability to take part or interest in the study, rather than the photography method itself.

Lessons learnt

Trying to recruit to this study was time-consuming and very disheartening. I tried to follow advice, such as keeping the demands of the study to a minimum for both patients and staff (Ross et al 1999), being approachable and contactable for both patients and staff (Patel et al 2003), producing relevant information consistent with the needs of this patient population (Ziegler et al 2004) and giving regular feedback to staff (Patel et al 2003). However, I think I had underestimated the huge physical, psychological and social burden of the diagnosis and treatment for this particular patient group, which placed my study way down their list of priorities. I also underestimated the need for a more direct approach and face-to-face information giving about this very novel approach and the aims of this study. I tried to 'protect' participants by using information packs that ensured confidentiality and were intended to avoid potential participants from feeling coerced into taking part, However, this approach also prevented me from being able to follow-up those who had taken or received the packs in order to either recruit them or to find out why they had not responded and amend the study accordingly.

Conclusion

This study failed to recruit enough participants to adequately assess whether participant-produced photography is an acceptable, practical and relevant method of data capture in which to explore the experience of living with and beyond cancer from the perspective of people whose ability to communicate verbally has been seriously affected by head and neck cancer and its treatment. However, the two participants who did use it created some interesting and promising photographs. They both reported enjoying the process and had not found it too onerous. These two cases are described in chapter six.

The data produced by the participants gave me enough optimism to continue pursuing the use of visual methods to illustrate the experience of living with and beyond a cancer diagnosis but the lessons learnt from the very difficult recruitment process informed me that I would need to re-think my participant group and research process significantly and manage my next study very differently. The methods and process of the resulting study are described in chapter seven.

Chapter 6

Feasibility study: Results and observations

Introduction

As described in chapter five, only two participants were enrolled into the feasibility study. It was hoped that five participants would be recruited to give a better assessment of whether participant-produced photography is acceptable, practical and relevant for an exploration of the experience of living with and beyond cancer by people whose ability to communicate verbally has been seriously affected by head and neck cancer and its treatment. However, the two participants who did consent were able to fully engage with the study procedures, created some good quality and useful images and some original information was described by their photographs and their responses to them. The results are described here as two case studies.

Participant 1: Background and data collection

The first participant was identified as a potential candidate by consultant one during a follow-up visit at UHCW where I was able to see him and speak to him about the study immediately. He was a South Asian gentleman who described moving to Coventry from India a "long time ago" with his wife to find work. He was sixty-seven years old and now a retired widower who lived alone. He had a daughter who lived nearby and visited him often. He had received his diagnosis of laryngeal cancer fourteen months previously and had been treated with surgery and radiotherapy. He had a laryngectomy and spoke through a speaking valve which he seemed to have mastered although using it appeared to make him very short of breath. He could answer the phone but was only really able to say one or two words in sequence and tended to use gestures, if possible, to communicate.

On our first meeting in his home, he was very positive and said he had no problems or concerns about his condition and was keen to express his satisfaction with the care he had received. He was enthusiastic about taking part in the study and gave written consent. However, he did not own a camera, was not familiar with taking photographs himself and had never used a digital camera before. I spent some time showing him how to use the camera that he borrowed until he felt confident that he would be able to take some pictures to illustrate his experience and we arranged a date for me to return and look at the photos and any notes he had made about them two and a half weeks later. I called him during this time and he reported not having any problems with the process. When I visited him again he presented seven photographs which we printed off using a mobile photo printer and discussed each one in turn.

Participant 2: Background and data collection

The second participant was identified and given an information pack by the HNC clinical nurse specialist at UHCW. She said she was keen to take part and I arranged to meet at her home.

She was a white British thirty-eight year old woman who had lived all her life in Coventry. She was married and a full-time mother of five school-age children. She had received a diagnosis of oral cancer twenty months previously which had been treated with surgery, including skin grafting. She was able to verbalise well when I first met her but the HNC clinical nurse specialist said she had found speech difficult for several months after surgery and he considered that she had persistent problems with talking about her experience, which he thought may have been because she did not want to become upset in front of her children.

When I met her, she was able to verbalise clearly and was very positive, expressing no post treatment worries or problems. She was also extremely proud of being a 'cancer survivor' and was a keen and confident amateur photographer who had her own camera and enjoyed taking photographs which she regularly shared with friends online. She presented ten photographs and was able to e-mail them to me before our second meeting a month later so that I could print them beforehand. She also had several others that she wanted to talk about but not give me for the study analysis.

Because I had thought that most or all participants for the study would be unable to verbalise well, I deliberately did not plan to record the interviews with them. Instead I made field notes to record incidents, verbal and non-verbal communication and reactions that occurred during both visits. In retrospect, it would have been helpful to record them, particularly with participant two as she spoke very eloquently about each photograph and how it related to her experience. Both participants had also been encouraged to make notes to explain photographs they had taken and why although neither had done this.

Data analysis

The focus of analysis was whether data would be produced by this method of collection, whether the photographs produced would be of sufficient quality to be used as data and whether participants were able to convey experience and meaning through this method.

Rudimentary analysis of the photographs was possible for each participant although it was not feasible to analyse the photographs as a collection and attempt to draw out interconnected themes as there were so few. This made a formal approach such as 'layered analysis' impossible (Dowdall and Golden 1989, Oliffe et al 2008) but I was able to explore the relationships between the visual, verbal and field note data, as recommended by Pink

(2007). This focused on the experience of living with and beyond head and neck cancer and involved a detailed examination of each photograph and related documentation to seek an understanding of each participant's intended representations and a development of their interpretations of the photographs.

Results

Perception of the self and appearance following surgery

Both participants presented above shoulder portraits of themselves taken by other people which showed their current facial features. Despite both expressing huge positivity about their lives after cancer, they were both visibly upset by what they saw (see figure 2: perceptions of self and appearance).

Figure 2: perceptions of self and appearance

| **Photo 1** | **Photo 2** |

Participant one said he hated his laryngectomy (photo 1). On questioning further, it wasn't the management of it (which he found easy) or speaking through it but its appearance that he found difficult. He felt this was a particular problem and less acceptable within his culture. He said that looking at himself now made him feel "bad" and "unhappy". This was reflected in the unhappy way he spoke and appeared when he looked at this photo.

Participant two's scars were now barely perceptible to an 'outsider' and she had been told by her friends that they were impossible to see (photo 2). However she was very conscious of them and, to her, her face had changed considerably. She felt that her mouth drooped unacceptably on one side. Because of this, she said she was reluctant to smile in photographs (although she had a very cheerful personality and smiled frequently while discussing her photos). Talking about this and observing the photo made her cry, halting the discussion for a few minutes (something she said she rarely did and felt embarrassed about).

Furthermore, while going through her photos during this visit, she noticed something which she claimed never to have noticed before, i.e. in photos of herself in which the arm was visible from which she had had skin grafts taken for her face and neck, she always turned slightly or positioned her arm in a way that hid the scarring. She was surprised at this as she felt that this must indicate that the skin graft scar on her arm troubled her more than she'd ever realised.

The importance of close family and friends

Both participants produced photographs of close family members and friends (not reproduced here because consent for reproduction by the individuals in the photographs cannot be confirmed). Participant one had taken a photo of his daughter helping him wrap a gift for someone and participant two had taken many photos which included her husband and children. Both expressed how important these people had been to them at the time of their diagnosis, during their cancer treatment and at all times since. Their love and support was very much appreciated and both spoke proudly of them and were pleased to share their photos of them.

Although both participants had lost some friends who had seemed to avoid them since their diagnosis, the friends who had remained with them throughout their treatment were extremely important to them and very much appreciated. Participant two described them as "my other family". Participant one had a group of friends who lived in London but had come to visit recently and he had taken photos of them and expressed how important these visits were and how much he missed them when they went back home. Again both spoke proudly of them and the support they had given them and both expressed how this had altered their perception and they now valued those people who had remained their friends more.

The sanctity/loneliness of a private space

Both participants had taken photographs representing a private space but each carried very different meanings (see figure 3: the loneliness of a private space and figure 4: the sanctity of a private space).

Figure 3: The loneliness of a private space

For participant 1 this was his back room and kitchen (Figure). He appeared dejected when describing them as "where I live". On further questioning, he admitted rarely leaving these two rooms due to his anxiety about the appearance of his laryngectomy and he only left

the house for essential trips, such as hospital appointments and shopping. For him, his home seemed to represent a place of loneliness and isolation.

Conversely, participant two had taken some photos of flowers to represent the garden she loved and had labelled them 'beauty' (figure 4). She described her garden as "only small but my own private space" and enjoyed the solitude and "me time" it gave her. She said that she had not appreciated it before her diagnosis but had become interested in gardening since and loved sitting in it on her own and enjoying the quiet now.

Figure 4: The sanctity of a private space

New perspectives

Participant two presented several photographs of her and her husband enjoying days out together (see figure 5: new perspectives). She said that before her diagnosis, her children had been her only focus and she and her husband had rarely spent time just with each other. Her greatest fear when she was going through treatment was that her children would be left without a Mum. However, she had a strong Catholic faith and a priest had helped her realise that there were people who loved her and who would love her children and ensure they were safe, well and not alone if anything was to happen to her. He also persuaded her to put herself first sometimes. As a consequence, her perspective had changed a little and she and her husband tried to make time for themselves. She said that

she had found this very helpful and it had made her much happier. In fact, this change of focus meant she was less anxious and enjoyed life more now than she had before she was ill.

Figure 5: new perspectives
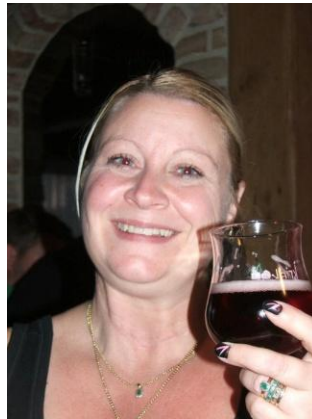
Moving on but retaining "the badge"

Participant two revealed some additional photos that had been taken when she was still in hospital after surgery showing her fresh wounds, etc. She said they were important to her to remind her of what she had been through but she wanted to reject them now and "move on". She wanted to replace these with a photo of a tattoo of the blue head and neck cancer ribbon, which she referred to as "her badge" (see figure 6: "the badge"). She had had this done after her treatment to show that she was a survivor and that her cancer was important to her and she was proud of what she had been through.

Figure 6: "the badge"

Principal findings and discussion

The prime motivation for this work was to investigate whether, in practice, participant produced photographs would be of sufficient quality and quantity to be used as data and whether participants were able to convey experience and meaning through this method. Despite participant one's inexperience, both participants produced a number of photographs illustrating different aspects of living with and beyond head and neck cancer and all were of good quality. Both participants were able to talk about each of their photographs, why they had taken them and what they meant.

Research evaluating the outcomes of HNC has been criticised for concentrating on the physical and psychological impact of the disease, whereas the social factors involved in adapting to a diagnosis, treatment and side effects may be extremely important (Babin et al 2008). For example, the disease and treatment can impact on people's appearance and essential functions, such as eating, speaking, seeing and breathing. This may also profoundly affect social interaction, emotional well-being and role function (Paterson et al 2002, DAHNO 2008). This was illustrated here where both cases focused on key themes illustrating some of the social aspects of living after treatment.

The photographs of themselves showing an altered appearance post-surgery produced strong negative reactions from both of them. The significant impact of HNC treatment, particularly surgery, on body and facial image is recognised, although poorly explored, and has been linked to anxiety in public, loss of self-esteem and other symptoms of social distress (Babin et al 2008, Semple et al 2008). In a large study evaluating patient reported factors influencing the decision to discontinue employment after HNC treatment, more than 17% of respondents chose to due to changes in appearance alone (Buckwalter et al 2007). Such altered identity can lead to a sense of marginalisation and exclusion, as illustrated by participant one's self-imposed isolation and admitted loneliness. QOL questionnaires and evaluations, commonly used in clinical practice and psychosocial research, are relatively vague about the practicalities of daily life, leisure activities and social relationships (Babin et al 2008), which may mean that this is inadequately investigated. However, it is an area that deserves investigation, not least because social isolation has been linked to suicide (Findlay 2003) and, according to a large population-based study, people with HNC have the highest incidence of suicide of any cancer site (Kendal 2007).

Social support and the importance of family and friends was also a key photography topic for both cases and has been recognised as an important factor in many studies of coping and adapting to HNC for both emotional and practical reasons (Semple et al 2008). Importantly, having a large social network has been associated with less depressive symptoms post-HNC treatment (De Leeuw 2000).

Participant two took photos to illustrate a renewed appreciation for life, her husband and "me time". Such positively changed priorities after HNC treatment have been explored by Thambyrajah and colleagues (2010). They also found that self-empowerment, greater

confidence, new hobbies, beneficial health changes and improved family relationships have been shown to be possible in spite of marked adverse effects.

The possible reasons for poor recruitment

People with HNC have been identified as a 'hard to reach' population, possibly due to their high incidence of social deprivation, anxiety and/or depression and long-term functional problems (Whale 1998, Paterson et al 2002). Of twenty seven people identified as potentially able to take part in this study over a about a six month period, six were eventually not approached due to the detection of progressive disease, reflecting the poor outcome associated with this cancer site (DAHNO 2008). Ultimately, only these two participants agreed to take part. It is not known what motivated participant one to take part. Participant two had altruistic reasons associated with information giving, saying she wanted to take part in "anything that would help spread the word". The five identified potential participants who gave a reason for not taking part stated individual reasons associated with their interest in the study or research generally, their ability to take part or personal gain.

The representativeness of the cases

There can be no claim made that two case studies typify a cancer 'population'. However, both participants lived in areas with a high incidence of head and neck cancer (Oxford Cancer Intelligence Unit 2010). Participant one was representative of the greater incidence of HNC in the UK from South Asian communities (mirroring the high incidence in India, Pakistan and Bangladesh) (NICE 2004). Furthermore, although HNC is more common in men, this is changing. The male to female ratio for oral cancer in the UK has decreased rapidly from around 5:1 fifty years ago to less than 2:1 today (Cancer Research UK 2010[B]). Also, an increasing number of young people are being diagnosed worldwide; up to 5.5% at

less than forty years of age (Toner and O'Reagan 2009). Reasons are unclear although there is an association with Human Papillomavirus (HPV) infection (NICE 2004). Therefore, although it is still unusual for young women to receive a head and neck cancer diagnosis, participant two represents a growing minority. However, because of the unique experiences of these two participants, some aspects of living after HNC which may be important, such as returning to work (Buckwalter et al 2007), could not been explored.

The potential of using participant-produced photographs

HNC treatment or the disease process can cause speech loss or significant speech impairment in up to a third of patients. Because studies exploring living with illness often rely on interviews (Holstein and Gubrium 1997), people with HNC who are left with significant speech problems may be excluded, even though their needs following 'survival' would appear to be considerable and complex (Thambyrajah et al 2010). Therefore, photography, which does not rely solely on the ability to express oneself verbally (Palibroda et al 2009) appeared to offer an important alternative for participant one.

Pink (2007) proposes that the camera, when used in personal spaces, such as the home, can create important data about everyday experience and allow the space to be a prompt through which people can express their identity and experience. This was true for both participants. Their photographs allowed me into the environments in which they lived and introduced me to their social networks. Through that, they were able to express and subsequently explore aspects of living with HNC that they themselves had not been consciously aware of or able to speak freely about, such as issues around body image and isolation, and which therefore may have been missed in a traditional interview.

Although there has been a huge increase in awareness of the quality of life issues surrounding this disease, it is recognised that much more research into 'extra-medical' problems and the "integration of the disease into daily life" is needed (Babin et al 2008). Using participant-produced photographs to gather such data holds theoretical promise, especially for a population that may be limited in verbal communication. As far as I am aware, this is the first time this potential has been tested practically in this population. Methodologies such as this now need more rigorous assessment with bigger study populations in order to test and develop the developing themes that were revealed here.

Conclusion

Two case studies in which participant-produced photography was used to allow people to communicate their experience of receiving a diagnosis for and treatment of head and neck cancer have been presented here. Despite one participant being very unfamiliar with using a camera, the data returned was of good quality and quantity and the participants said they had enjoyed the process and had not found the method too onerous.

Although the data was very limited being collected from only two participants, some recurrent and key themes were identifiable. The photographs also allowed the detection and probing of information that would otherwise have remained hidden if the verbal interview had been the only source of data.

These two case studies offer a hint of the practical potential of using participant-produced photographs to augment and probe qualitative data and allow those with an absent or limited voice to 'speak'.

The succeeding principal study, describing in the next chapters, continues the exploration of living with and beyond cancer by employing participant-produced photographs to add data to qualitative research interviews.

Chapter 7

Principal study: Method and process

Introduction

In this chapter, I describe how I performed the principal study. This includes an account of

my choice of method (photovoice modified from the originally outlined procedure to make

it more appropriate and pragmatic for my particular population), recruitment including the

strengths and limitations of the recruitment process, the characteristics of the participants

and representativeness of the final sample, issues of confidentiality and copyright and how

they were addressed and the method and process of analysis.

Background

The promising data created by participants one and two recruited to my feasibility study

(described in chapter six) had made me very optimistic about using participant-produced

photographs to learn about the experience of cancer. However, the recruitment strategy

had been unsuccessful and too slow to realistically continue to recruit from just this single

group of patients, given the limited time and financial constraints of a PhD. However, just

prior to reaching this stage I had been awarded a research training fellowship for nurses,

midwives and allied health professionals from the West Midlands Strategic Health

Authority. This gave me 75% full time equivalent funding to continue my work and

consequently allowed me to diversify from and not work wholly with people with head and

neck cancer. On reflection I realised that there may be more groups of people with cancer

who are unable to take part in research employing such interview methods only due to

impaired or painful speech, for example, people with dyspnoea caused by lung cancer,

people with stomatitis following chemotherapy or people with pain and difficulty

swallowing after radiotherapy to the upper thorax. There may also be others who find it

difficult to communicate verbally and explain certain aspects of living with and beyond cancer simply because they find it difficult to 'put things into words', possibly due to emotional, psychological or semantic reasons. As Lawton (2003) says, reliance on interviewing in qualitative research means there are still many voices missing from the literature on health and illness and researchers need to be more flexible in their adoption of alternative and sometimes unconventional data collection methods if they wish to capture the whole illness spectrum. I therefore decided to continue to develop a full empirical study using visual methods but to widen my participant group and expand my recruitment strategy.

After carefully consideration, I decided to recruit people who had been diagnosed with any 'poor prognostic' cancer, which now constitutes about 50% of common cancer diagnoses, as shown in table 5 overleaf (Cancer Research UK 2009[A]).

I would have preferred to have recruited from one 'type' e.g. women with ovarian cancer. This would have increased the generalisability of the study and allowed a more thorough investigation of the particular concerns of an individual group (Mason 1996). However, fears about being unable to recruit from a single group as before forced me to be pragmatic. By recruiting those diagnosed as having a poor prognostic cancer, defined as a likely survival of less than 50% at five years (Cancer Research UK 2009[A]), I believed I would still be able to address whether these people were able to associate themselves with "the culture of survivorship" (King 2006, p 101) or whether this gave them a different perspective and experience of their diagnosis, compared to the experience of people with more 'survivable' cancers (Ehrenreich 2001). However, I would have a much larger pool of potential participants.

Table 5: Relative five year survival estimates based on survival probabilities observed during 2000-2001, by sex and site, in England and Wales (after Cancer Research UK 2009[A])

Five-year relative survival
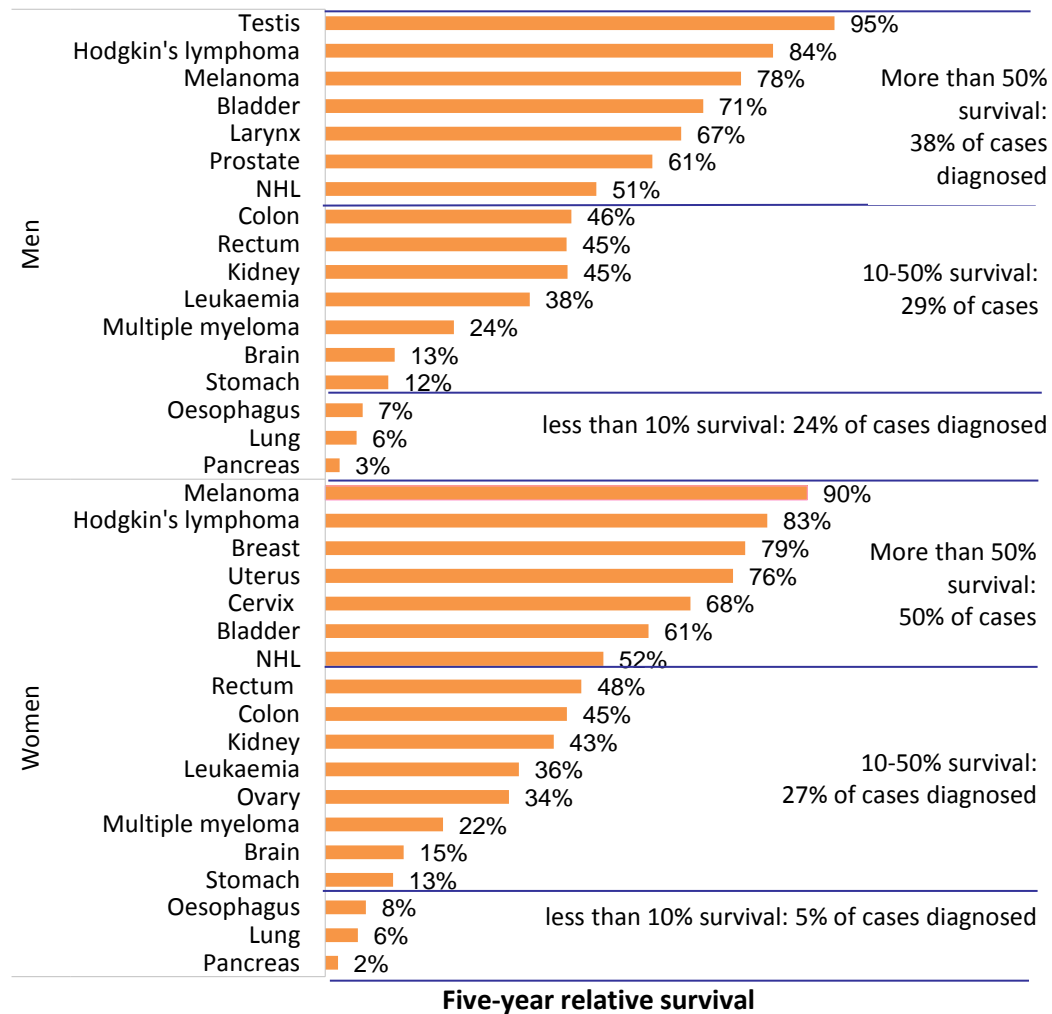
I also hoped to gain ethical consent which would allow me to bypass the secondary care system with its focus on treatment if necessary and recruit some participants from the community. I thought the best way to do this would be to make information available via established support groups, cancer organisations, charities and other establishments accessed by people living with and beyond a cancer diagnosis. I expected that there might have been questions raised by the research ethics committee about 'advertising' for participants in this way but I took Dyas et al's (2009) advice to maximise the recruitment

strategy as early as possible and began to consider the most appropriate way to do this while maintaining safety and anonymity.

Study aims

The overall aim of this study was to explore the experience of living with and beyond cancer, using a symbolic interationist framework and from the perspective of people diagnosed with a 'poor prognostic' cancer, particularly within the context of cancer representation in contemporary society.

The aim of the feasibility study had been to investigate the acceptability, practicability and relevance of using photography as a method of data capture. Although the two participants recruited had shown that this was acceptable to them, this also needed exploring further due to the very limited number of participants.

Choice of method: Modified photovoice

The method I chose to use is known as photovoice. The history and principles of the photovoice method have been discussed in chapter 4. The primary goals are to:

- Enable people to record experience and concerns through the creation of their own photographs

- Provide information and promote critical dialogue through a discussion of the photographs

- Reach decision makers through public dissemination of the photographs

López et al 2005.

Photovoice was originally developed as a participatory action research method and a way of engaging participants in group discussions and presentation of images (Wang and

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Redwood-Jones 2001). Although this has worked well when the research has arisen from community projects e.g. Wang's work with a Chinese womens' community group (Wang and Burris 1997, Wang 1998), it has often been necessary to modify the method to assimilate the particular population involved, for example so that physical limitations and/or the impracticality and financial restrictions of attending group sessions can be incorporated (Baker and Wang 2006, Castleden et al 2008, Catalani and Minkler 2010). It is now common, particularly when working with people who are ill, for participants to create and discuss their images on an individual basis, as accomplished by Baker and Wang (2006) in their study of chronic pain in older people and Oliffe and Bottorff (2007) in their study of men with prostate cancer. It was impractical for many of the participants in my sample, who were eventually recruited nationally, to meet and work together, so I met them and they took and discussed their photographs with me on an individual basis. I also believe that group interviews about living with and beyond cancer might have inhibited some of the rich and personal data that was ultimately gathered. However, to incorporate the communal principles of photovoice as much as I could, I also planned to hold some meetings for participants to meet each other and discuss their images collectively if they wished. This is discussed later in this chapter.

Study support

User involvement

User involvement in healthcare research developed during the 1980s and the National Cancer Research Institute have supported and advanced it since it was founded (Brown et al 2006, Wright et al 2007). Although there have been criticisms of it, for example in the representativeness of those who volunteer to become involved or the risk of 'professionalising' users (Wright et al 2007), I was keen to find out how people with personal experience of cancer considered the research proposal and plan, particularly the

study question and novel methodology. I was also uncertain about the use of the term 'poor-prognostic' within the written participant information. I did not want to present it starkly to people who were perhaps not aware or not ready to consider their prognosis but felt that ethically it should be included or people might be signing up to something without the full information and hoped the user group would advise me. The study plans and protocol were discussed with a user group consisting of three women with breast cancer diagnoses, one man with a head and neck cancer diagnosis and the carer and wife of a man with a head and neck cancer diagnosis. All these people had previously worked within national user groups and were well versed in user group policy and procedures. Useful advice was given about the wording of the Participant Information Leaflet resulting in its amendment prior to Research Ethics Review. Also, most of the user group were reticent about the term 'poor prognosis' so it was decided to exclude it from the written material but I would discuss it with each potential participant before they gave consent. Otherwise, the study plans were seen as relevant, the method as inspiring and the study was supported by the group.

Clinical staff

I decided to continue to try and recruit from University Hospital Coventry and Warwickshire (UHCW) as it housed the local cancer centre (Arden Cancer Centre). I spoke to four consultants (three clinical/medical oncologists and a HNC surgeon) with whom I had links and all agreed to support the study. I also set up a meeting with the research nurse team where I presented the study and requested help from them.

A former colleague who is a consultant medical oncologist at the Dorset Cancer Centre, Poole Hospital Trust (PHT) was also keen to be involved. I arranged a meeting to present

the study to him, cancer nurse specialists and research nurses at Poole and they agreed to open the study there.

I was also offered help in recruiting from a local palliative care consultant and research nurse but unfortunately the research governance procedure at the local hospices was protracted and I was unable to open the study there before recruitment ceased.

Cancer organisations, charities and support groups

The consultant at PHT advised me to contact the chair of Cancer 52, with whom he had recently completed some commissioning work, as he felt he would be interested in the research and might be able to assist recruitment. Cancer 52 is a national alliance of organisations that represent the less common cancers, which are responsible for 52% of UK cancer deaths, and are largely under-represented in UK services and research (http://www.cancer52.org.uk/). As such, many of the members of Cancer 52 represent the particular people I wished to recruit and I hoped that I would be able to find some potential participants via them. I spoke to the chair and provided him with a short précis of the study from which he disseminated details to Cancer 52 members. I also located several local support groups that I planned to contact when the study started to recruit.

Ethical approval

The protocol and related documentation were prepared during the autumn of 2010 and submitted for Research Ethical Committee and NHS Research Governance approval. I was granted ethical approval in late November 2010 and NHS approval for UHCW and PHT in December 2010. I had fully prepared the clinical staff at the two hospitals and was therefore able to provide the necessary paperwork and open the study sites as soon as

approval was given. I also contacted Cancer 52 to let them know that recruitment could start.

Planned study process

Inclusion criteria

The inclusion criteria were:

- People with a diagnosis of histologically or cytologically proven cancer which usually carries a poor prognosis, defined as those cancers which have a five-year survival estimate of less than 50% (Cancer Research UK 2009[A])

  ❖ For example, ovarian cancer in women, oesophageal cancer, pancreatic cancer, lung cancer, some oral cancers, brain cancer, leukaemia (Cancer Research UK 2009[A])

  ❖ A diagnosis of another cancer which has been defined as having a poor prognosis for reasons other than its site, e.g. metastatic breast cancer or non-Hodgkin's lymphoma in an over sixty-five year old (Cancer Research UK 2009[A])

- People not actively involved in treatment (i.e. have completed treatment and are not receiving supportive or maintenance therapy which requires frequent in-patient or follow-up visits)

- Adults (age≥18 years)

- People able and willing to give informed consent to participate in the study

- People able to take part in an English spoken interview.

I chose not to include people who were still actively involved in treatment demanding frequent follow-up because I did not wish the study procedures to be too onerous for them. I was only able to recruit people who could take part in an English spoken interview due to the financial constraints of employing interpreters.

Because it was intended that some participants would be self-referrals, I was unable to verify diagnoses and prognoses with any clinical information and was not certain how informed potential participants would be. As discussed earlier in this chapter, the information sheet was carefully worded as advised by the user group and I sensitively questioned people who enquired about the study to try and elicit their understanding. All the people who contacted me appeared to be fully informed about their diagnosis and prognosis and happy to discuss it in regard to their eligibility.

Participant identification and enrolment

As with the feasibility study, I provided the consultants at the two hospitals with study invitation packs containing an introductory letter, participant information leaflet, reply slip and SAE, addressed to myself, for them to give to any potential participants they identified. Three charities, who were affiliates of Cancer 52 (Oesophageal Patients' Association, Ovarian Cancer Action and Mouth Cancer Foundation) e-mailed information to their members and supporters and referred people to me who expressed an interest in the study. I also e-mailed several local, appropriate patient support groups. Hammer Out Brain Tumours (support group based in Worcester) and the Arden Cancer Network User Partnership replied immediately and were keen to help. I spoke at a Hammer Out support group meeting and the manager of the Arden Cancer Network User Partnership e-mailed appropriate users and referred interested people to me. With ethical approval, I also created a study Facebook page (http://www.facebook.com/pages/Living-With-and-Beyond-Cancer/160521737329504) so that information could be shared and discussed by and between myself, any interested recruiting groups or personnel, participants, user groups and other interested parties. I began to get referrals in January 2011 and recruited the first participant in February 2011. Further local organisations were identified as

potential recruiting sites but it was not necessary to approach them because recruitment remained constant.

By September 2011, I had recruited thirty participants and was still receiving self-referrals. However, interviews with participants did not seem to be revealing any significant new themes. Therefore I ceased recruitment at this stage.

Sources of referrals

The sources of the referrals (who were eventually recruited) are illustrated in figure 7. The 'other' category included a friend of a colleague, an employee of Cancer 52 and someone who accessed the study Facebook page.

Figure 7: Sources of referrals
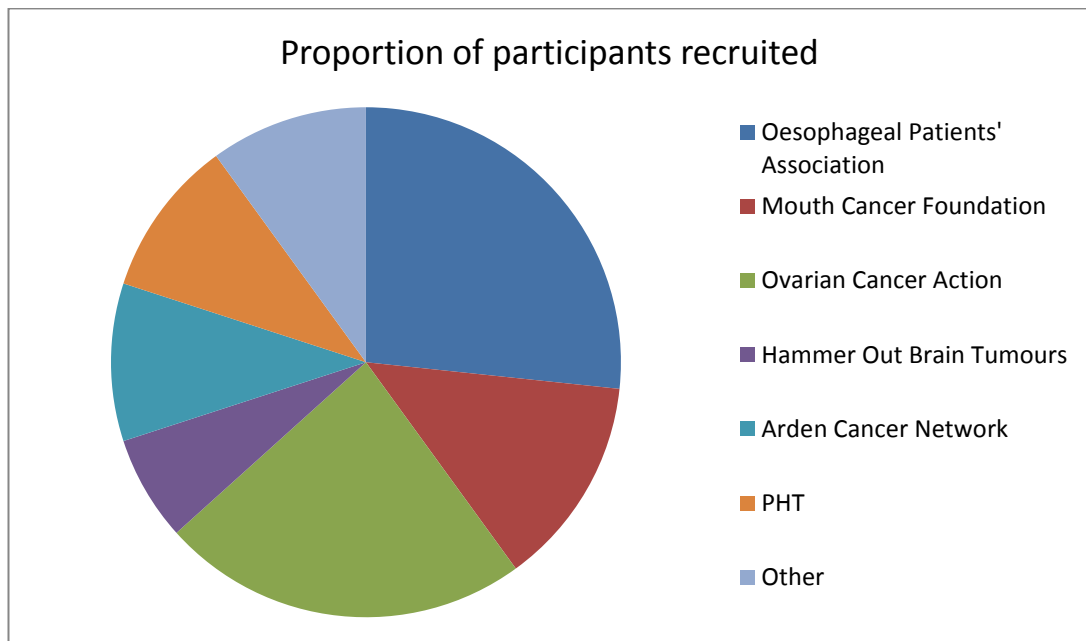
Strengths and limitations of the recruiting method

The strengths of recruiting participants via both clinical staff and information provided by organisations meant that recruitment was quick and complete and that motivated people

who were interested in the method used and happy to talk freely about their experience were recruited. Furthermore, the study became a national one in which participants were recruited throughout England giving a wider perspective, unbiased by regional cancer policy or service provision which may have affected participants' experiences.

However, because information about the study was taken up in an ad hoc basis by organisations who were interested in the research and/or method, it was only disseminated to those organisations' members and supporters, resulting in a sample biased towards some cancer types. For example, no lung cancer specific organisations or support groups expressed an interest in the research and consequently I recruited only two people with lung cancer; a very small number in proportion to the number of people diagnosed with lung cancer in the UK overall. Furthermore, participants who referred themselves via information received from cancer organisations and support groups may have been different from people with cancer generally. Steginga and colleagues (2008) found that people who accessed psychosocial support services after a cancer diagnosis were much more likely to be female, younger and have greater cancer-specific distress. This has also been reflected by UK surveys of cancer support group attendees (Grande et al 2006, Stevinson et al 2010). However, by recruiting to the inclusion criteria detailed above, the sample retained specificity (Mason 1996) and should have been valid enough to explore the phenomenon of cancer experience, without necessarily being applicable to the whole population of people with cancer (Bowling 1997).

Study procedures

Data collection

Participants were offered a choice of venue for their interviews. Most chose to be interviewed in their own home although two chose independent places (a cafe and city

park). At the initial visit, I gave potential participants any additional information they required and a consent form. The consent form explained that they could withdraw from the study at any time, that participation was voluntary and would not alter their treatment in any way and that all personnel information would be kept confidentially and securely. All were happy to give written consent. We then had a loosely structured and tape-recorded interview based around the themes of living with and beyond cancer in contemporary society. Many participants covered the categories I had hoped to discuss without prompting but I had devised the interview schedule illustrated in table 6 to ensure that pertinent themes were considered and explored. Initial interviews lasted between thirty minutes and two hours twenty minutes (usually eighty to ninety minutes). My interviewing style was checked by another researcher who listened to my first few recorded interviews.

Table 6: initial interview schedule

Main question	Probing questions	Themes
How did your life change when you were told you had cancer?	What went through your head when you were given your diagnosis? How did you tell family/friends/colleagues? How did your family/friends/colleagues react? Did anything change immediately? *If yes, what?*	'Perception' of cancer (participant/ others). Social support. 'Sick role'.
What is it like to survive cancer and cancer treatment?	What do you do differently since finishing your treatment*? – physically, socially, the way you think about things? Do you do more/less? Why?* How do you manage life since having cancer – *e.g. do you worry more/less, have you put it behind you?* Do you see yourself as a 'cancer survivor'? *Why/why not?*	Social roles. Self-esteem. Hopefulness/ hopelessness Concept of 'survival'.
Do you think there is anything particular about living in our society today that has affected your experience?	Do you think people who have had cancer are expected to behave in a certain way/be a certain type of person? If yes, w*hat is this? Do/are you?* How do you relate to stories in the media of other people with cancer? – *e.g. celebrities & 'ordinary' people – Helpful/unhelpful? Why/why not?* How 'true' is the picture about cancer that is painted? What would you like people/society to know about 'living with and beyond cancer'?	Media representation. Cultural images. Metaphors about cancer. Information/ communication about cancer. ⟹ Impact on people with cancer.

Although preceding the actual photovoice process, an initial interview commonly takes place in studies using visual methodology (Rose 2007). For example, Brooks and colleagues' work with Aboriginal women with breast cancer (Brooks et al 2008), Oliffe and colleagues' study about new fathers who continue to smoke (Oliffe et al 2008) and Radley and colleagues' work with homeless people (Radley et al 2005). I found that this not only gave some rich and credible information with which to triangulate the photographic data and interview data specifically about the photographs (Catalani and Minkler 2010) but also seemed to help participants focus on areas their photographs were going to illustrate (Rose 2007) as many commented on this as they spoke about their experience.

I then requested that participants take photographs of anything that represented and signified 'living with and beyond cancer' for them. I deliberately asked that they use digital cameras to make it easier to transfer and view images and also to allow participants to confidentially delete images they chose not to share. All the participants were able to use a digital camera and most had their own which they used for the study. Only one participant borrowed a camera. Advice was given about confidentiality and photography (see 'confidentiality and ethical issues' section below).

I had previously attended a training course at the London-based charity Photovoice (http://www.photovoice.org/). There we had been given advice about how to motivate participants and advise them about subject matter. I gave people some tips based on this although most had begun to identify representative photographs before or during the initial interview. I avoided referring people to examples of photovoice studies in case this influenced their final choice of photographs.

During the initial visit, each participant and I arranged a convenient second visit for two to four weeks hence. This time was specifically chosen as I hoped it would be a period long enough to allow participants to consider, take and reflect on their photographs without allowing so much time that it would cease to become a priority for them. Participants were asked to choose and, if possible, send about five to ten of their most representative photographs to me a few days before the visit so that I was able to attend with already printed photographs for discussion; all were able to do this. I called each of them during their photo-taking period to ensure they had no problems using the camera, with the photography process or choosing themes/subjects to photograph. They were also encouraged to call or e-mail me if they 'got stuck' but nobody did.

At the second visit, the participant and I viewed prints of each participant's chosen photographs and a further tape-recorded interview took place based around the photographs, what they represented and why the final five to ten had been chosen. Again, I had prepared an interview schedule which related to the three sites at which Rose (2007) argues that the meanings of images are made; their production, the image itself and the intended audience (see table 7 below). However, as before, most people gave me the information I had hoped to collect without prompting.

Table 7: Photograph interview schedule

Production	Image	Audience
How did you feel when you took this photo?	What does this photograph depict?	What do you want other people to see when they look at this photo?
Did you take it for yourself/someone else?	Why did you take this particular picture?	If other people were going to see this photo, where would be the best place to display it?
How are you related to the people/things/place in this photo?	What do you like/dislike about this photo?	Why do you NOT want this photo to be seen? *(rejected photo)*

These interviews took between twenty five minutes and two hours forty minutes (usually approximately forty-five minutes). A direct question was asked to all participants, which was, "How did you find the process of taking photographs to illustrate and demonstrate your experience?" Written consent was then taken for both photograph reproduction for educative and non-commercial presentations and publications of the research study and copyright (see 'copyright' section below) and participants were requested to complete a short data collection form about ethnicity, marital and socio-economic status (questions based on the 2011 English Census questionnaire, Office of National Statistic 2011[B]).

As suggested by interpretive researchers (e.g. Silverman 2000), field notes were taken to record incidents, non-verbal communication and reactions that occurred during both visits during the data collection and analysis session in order to clarify events at a later date. It was expected that some participants may have required more than two visits to complete the process but this was not the case. All participants were able to produce a number of good quality photographs and were willing to share them with me. There was no attrition throughout the study although three participants chose to do both interviews during a single visit, two because they had already taken the photographs they wished to use and did not want any time to take more and one had some subjects prepared and took photos at the visit after the first and before the second interview because he was planning to work abroad for a few months shortly after the arranged visit. One woman chose to have a second interview by telephone because she was busy moving house. Subjects were given copies of their printed photos and consent forms.

The interview data was transcribed verbatim and loaded onto NVivo8 software for ease and thoroughness of analytic coding (Seale 2000).

Confidentiality and ethical issues

I appreciated that there may have been concerns about the confidentiality of visual data produced (Prosser and Loxley 2008, Wiles et al 2008). I therefore contacted researchers who had previously utilised this type of data collection in the UK healthcare setting in the study planning stage and sought their advice (Frith and Harcourt, Radley and Taylor). The Statement Of Ethical Practice For The British Sociological Association – Visual Sociology Group (2006) and Photovoice Statement of Ethical Practice (2009) was also incorporated into the study protocol.

As such, written and verbal advice was given to participants advising them:

- To avoid taking photos of other people without their knowledge

- To avoid names of buildings, house numbers, etc. when taking photos of a place

- To seek specific permission from every person depicted in a photograph before keeping the photo for the study

- That photographs of people could be reproduced with faces or other features blurred if requested so that they are not immediately recognisable (but participants were advised that body shape, association and other factors may distinguish individuals).

- That although all photographs would be used for analysis, none would be used within any publication or presentation without the individual's specific and signed consent.

(Ethical issues concerning visual research are discussed in more depth in Chapter 4).

Copyright

Photographs are deemed to be 'artistic works' and the creator of the work is the copyright owner (Prosser et al 2008). For this reason, participants were asked whether they wished their name to be accredited to any published photographs. It was made clear to them that this may have removed their anonymity but would prevent anybody using the photographs they had consented to be shared for any other means. Approximately half the participants chose to copyright their photographs.

Characteristics of participants

Thirty participants were eventually recruited. The sample comprised twenty three women and seven men aged between twenty two and eighty two years (see figure 8). Twenty five participants defined themselves as 'white' (English/Welsh/Scottish/Northern Irish/British Irish), one defined herself as 'mixed/multiple ethnicity' (White and Black African), one defined herself as 'Asian/Asian British' (Indian) and three were 'not stated'.

Figure 8: Age range and gender of participants
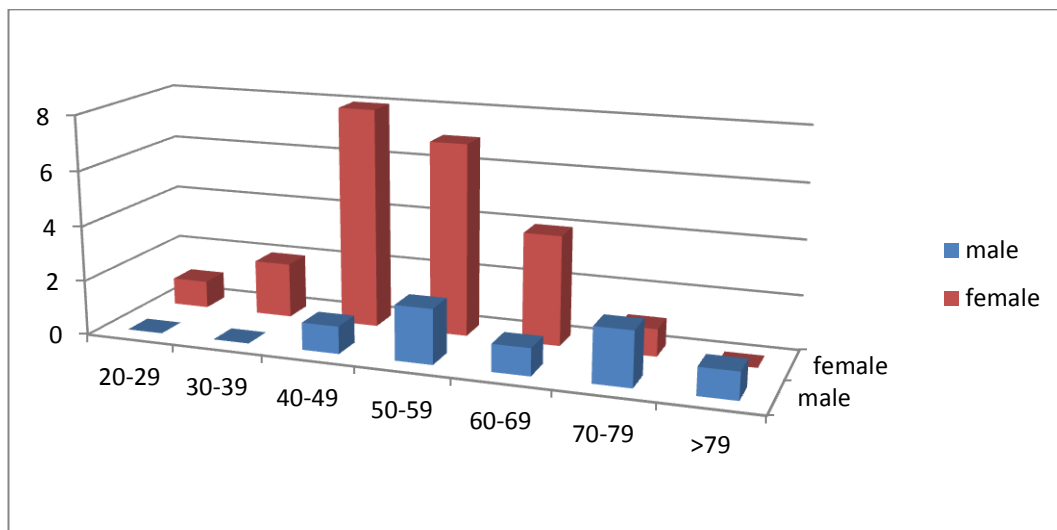
Although the sample consisted of people diagnosed with a poorer prognostic cancer, their time since diagnosis ranged from one to seventeen years, with a median of five years and there was a reasonably wide representation of cancer diagnoses as depicted in figure 9 and most people had received at least two treatment modalities (see table 8).

Figure 9: Diagnoses of participants
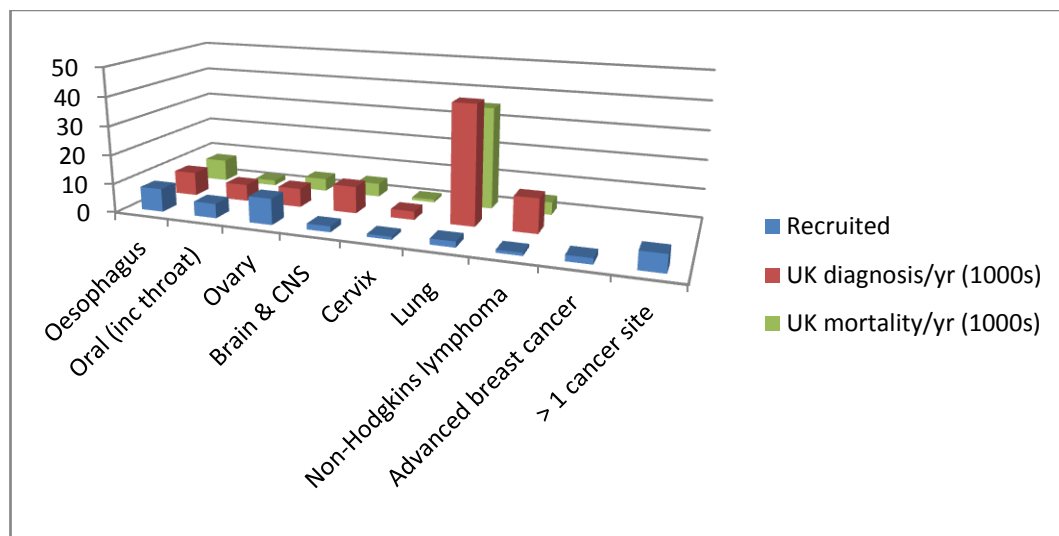
Table 8: Treatment modalities received

	Surgery	Chemo-therapy	Radio-therapy	Targeted therapy	Other
Number of participants who had received treatment modality	22	22	7	1	2

Sixteen people were married or living with a partner, seven were divorced or separated, five were single and two were widowed. Participants were also asked to complete a short data collection form about employment status, household income and financial support but the large number 'not stated' returns made this data difficult to interpret meaningfully (see tables nine, ten and eleven).

Table 9: Employment status of participants

Employment type	Number of participants
Working as an employee	7
On a government sponsored training scheme	
Self-employed or freelance	1
Working paid or unpaid for your own or your family's business	1
Away from work ill, on maternity leave, on holiday or temporarily laid off	2
Doing any other kind of paid work	
None of the above	9
Not stated	10

Table 10: Approximate gross household income/year

Gross household income/year	Number of participants
Up to £10,000	2
£10,000 - £20,000	2
£20,000 - £30,000	2
£30,000 - £40,000	4
£40,000 - £50,000	1
£50,000 - £60,000	
£60,000 - £70,000	1
£70,000 - £80,000	1
£80,000 - £90,000	
£90,000 - £100,000	1
More than £100,000	
Would rather not answer	2
Not stated	14

Table 11: Receipt of benefits or financial support

Do you receive any benefits or state financial support?	Number of participants
Yes	8
No	11
Would rather not answer	
Not stated	11

Representativeness of participants

The recruitment process was pragmatic rather than idealistic and the sample was largely convenient (although a former colleague who worked with people with lung cancer was encouraged to refer potential participants as no people with lung cancer self-referred and no local lung cancer groups responded to information sent). It is therefore not known how generalisable the sample is to the population of people living with and beyond cancer in the UK.

Furthermore, the sample may have been biased as the majority of participants self-referred. These people may have been more motivated and active in cancer-related activities than the general population and associated with their cancer for longer (Hubbart and Forbat 2011). It can be argued that only motivated individuals would take part in such a proactive and participatory method of data collection anyway but it must be realised that the findings of this study may make them less universal to the total population of people with a poor prognostic cancer diagnosis. The specific characteristics of the sample and the possible associated impact on bias are discussed below:

- Age

Although there was a wide range of ages represented, the median (fifty-three years) was lower than the general population of people with cancer in the UK, in which 63% of cancers are diagnosed in people aged sixty-five and over (Cancer Research UK 2011[E]). Greater age has been identified as one of the main factors that adversely affect research response rates (Patel et al 2003) and participation in cancer clinical trials (Lewis et al 2003). Furthermore, younger people are more likely to access psychosocial cancer support services and support groups (Steginga et al 2008, Grande et al 2006) which may have made them more likely to be exposed to information about the study.

- Gender

Men are at greater risk than women from nearly all of the common cancers that occur in both sexes (National Cancer Intelligence Network, Cancer Research UK, Leeds Metropolitan University and Men's Health Forum 2009[B]), however more than three quarters of the study participants were women, which reflects higher female response rate in other research studies (Patel et al 2003) and also access to cancer support services (Steginga et al 2008, McDowell et al 2011) and support groups (Grande et al 2006, Stevinson 2010). The greater number of women may also reflect the interests of the individuals and organisations which were particularly supportive of the study, for example the charity Ovarian Cancer Action were particularly helpful in referring potential participants. It was not possible to analyse any difference in the experiences of different genders due to the disproportionate number in this sample.

- Ethnicity

11% of the UK population consider themselves to be non-white (Office of National Statistics 2011[A]). Although people from Black and ethnic minority groups are at slightly lower risk of cancer overall (National Cancer Intelligence Network and Cancer Research UK 2009[A]), my sample did not fully represent the ethnic diversity of the UK. Being non-white adversely effects research response (Patel et al 2003), recruitment into clinical cancer research trials (Godden et al 2010) and access to cancer services generally (Elkan et al 2007). Reasons suggested have included costs, language and communication barriers, provider attitudes and socio-cultural barriers (Hussain-Gambles et al 2004) and also a perceived lack of commonality in shared stories about experience (Avis et al 2008). Because funding and time constraints did not allow me to employ translators, one of my eligibility criteria was that participants had to be able to take part in an English-spoken interview and all my

disseminated information about the study was provided in English, which may have also restricted recruitment from some ethnic groups.

- Disease site

Although my sample was representative of many of the poorer prognostic cancers, it was not always proportionally representative of the number of poorer prognostic cancers diagnosed nationally (see figure ten). For example, I recruited only two people with lung cancer, despite it being the third most common cancer after breast and prostate cancer, and none with pancreatic cancer, despite it being as prevalent as oesophageal cancer (Cancer Research UK 2010[A]). As discussed previously, the sample was biased towards the cancer sites represented by the individuals and organisations which had supported the study. Furthermore, the very limited likely survival (usually less than six months for pancreatic cancer) and co-morbidities often experienced with cancer sites such as lung and pancreas (Cancer Research UK 2010[A]) may have prevented their self-referral or referral by clinicians to the study.

- Time since diagnosis

Although the median was probably raised marginally by two women who had lived with better prognostic breast cancer before having a metastatic diagnosis, the median time since diagnosis was much greater than I had expected for a sample originally diagnosed with a poorer prognostic cancer and included four people who talked about living for more than a decade with the expectation or reality of disease progression. On average, the people surveyed by Steginga et al (2008) had not utilised cancer support services until more than a year and a half after their diagnosis and more long-term cancer survivors are likely to attend support groups (Stevinson et al 2010), indicating that some participants might not have had access to the study information until they had lived for some time with

their diagnosis. The active and participatory nature of the data collection may have made it less attractive to people who had had less time to fully get over treatment side-effects, etc.

- Other data

Unfortunately, due to a large number of 'not stated' returns, particularly regarding employment, household income and financial support, it is difficult to be certain how representative my sample was in terms of socio-economic criteria. However, it does appear that I had representation from a range of economic backgrounds. Similarly, my sample contained a mix of partnered and single participants.

Analysis

Data

The total data comprised 249 usable photographs and just over sixty two hours of narrative. Three people had downloaded one or more photographs from the internet to illustrate their experience. For example, one woman had downloaded a picture of a sleeping cat to illustrate the 'cat-napping' she had to do throughout the day to counteract fatigue and a man had downloaded a cartoon of a devil as an illustration of how he saw his cancer. Although these were interesting depictions, they were not used as they were not participant-produced and the copyright could not be verified. Some people wished to include pre-existing photographs rather than those taken specifically in the period between interviews to illustrate certain aspects of their experience and this was considered to be acceptable. Some people had asked family members or friends to take photos in order to include themselves. Although in this case, participants had not clicked the shutter, these were still considered to be 'produced' by the participants and therefore included. Three

people also wrote notes about their photographs and experience which they gave to me. These have been used as additional narrative to complement the interview data.

Timing of analysis

The analysis was a long, iterative process involving very close line by line scrutiny of the narrative in association with photographs. I started this as soon as participants began to complete their second interviews and give me their chosen photographs. As each transcript was produced, I loaded the interview data onto the CAQDAS package NVivo 8 for ease of coding. As Pink (2007) has noted, visual researchers have often been unenthusiastic about CAQDAS but I found the software invaluable for thoroughly examining and retrieving the interview data and comparing participants' first and second interviews (Seale 2000). Although pictorial data can also be loaded onto NVivo 8, the reproduction was limited in size and difficult to compare. It therefore proved easier for me to print the photographs as large hard copies and view them with the associated narrative. At first, many of the interview extracts and/or photographs seemed to represent more than one theme and were allocated several codes. In these cases interviews had to be listened to repeatedly until it was possible to categorise most appropriately. Codes were organised hierarchically into 'coding trees' in NVivo 8 to categorise and sub-categorise the emergent concepts according to their relationship with one another. Recurrent codes and similar aspects of living with and beyond cancer that were important to many participants began to emerge both from the interviews and photographs early and were noted. See NVivo8 screenshot example of coded interview in diagram 35 (appendix5).

After thirty participants had completed their second interviews, no significantly new topics appeared to be evolving from any of the data and theoretical saturation was considered to have occurred (Glaser and Strauss 1967). The formal analysis was completed after all the

photographs and interviews had been gathered and participants had had an opportunity to contribute to the analysis at the workshops (which are described later in this chapter).

Layered analysis

Many researchers who have used photovoice have explicitly avoided formal analyses of participant-produced photographs for epistemological reasons (Oliffe et al 2008). Although, like Brooks et al (2008), I believe that the participant's (photographer's) interpretation has the most important, if not absolute, meaning, I wished to avoid using the photographs simply as illustrations of the interviews (Radley and Taylor 2003). I also wanted to emphasize the photographic data and prevent the interviews taking precedence; a criticism that has been levelled at many social science researchers using photographs by Rose (2007). Therefore, I chose to analyse the photographs using a 'layered approach' as described by Dowdall and Golden (1989) and Oliffe et al (2008). This prioritises the photographic data and Oliffe and colleagues argue that a formal layered analysis can expand what is both said about, and interpreted through, photographs (Oliffe et al 2008).

Layered analysis was developed by Dowdall and Golden (1989) as a tool in which to examine a historical collection of photographs depicting life in a large mental [sic] hospital in the United States. Their approach consisted of three stages – appraisal (in which the photographs were viewed to see how the hospital presented itself and questions were raised for deeper investigation), inquiry (in which the whole collection was examined for themes) and interpretation (in which individual photographs were probed to explain phenomena that had emerged). This approach was adapted by Oliffe et al (2008) to analyse the photographs and incorporate the interview data they had collected for their ethnographic study about new fathers and their personal perspectives on their smoking habits. Using their framework, I analysed the photographs, interviews and any

accompanying notes in the four stage layered approach detailed below, focusing on the experience of living with and beyond cancer with a likely poor prognosis in a contemporary society:

1. An initial preview of each photograph and related first and second interview transcripts to seek an understanding of the participants' intended representations and how they site themselves within the content and production of the photograph. This involved moving repeatedly between transcript and photos for each participant on a case by case basis until they were formally linked. This privileged each participant's experience and interpretation and gave each photograph clarity and context (Oliffe et al 2008) and also helped direct me in further analyses.

2. A thorough and detailed review of the participants' interpretations of their photographs and the context in which they were produced to develop understanding and start to unpick multiple realities.

3. A reflexive and repetitive comparison of the entire photographic collection in which photos were tentatively coded at first and then re-categorised with increasing refinement. This was a very long process in which thirty four original codes were narrowed down to six key themes (see chapter eight for further details). Here I listened to the interviews repeatedly while reading the transcript and viewing the associated photographs and then coded the transcripts line by line. This constant comparison of the emerging codes and photographs occasionally revealed what, in my opinion, seemed to be contradictions both within and between participants' accounts and associated photographs. I considered these contradictions to be important as they sometimes highlighted ambiguities in the experience of living with and beyond cancer and informed the final theory. I also noted that some themes had been talked about in the first interviews but not

photographed and sometimes the number of photographs of a particular theme chosen seemed to be unrepresentative of the amount of talk devoted to that theme in the corresponding interview.

4. An interpretation of the categories in relation to appropriate theory.

It proved imperative to study each photograph thoroughly in the context of its associated interview before studying all the photographic data together as photographs that were ostensibly similar could portray very different topics. For example, five women had taken photos of their husbands or partners which were very comparable (not reproduced here because of confidentiality). Each was a head and shoulder shot of a man in his forties or fifties who was the only or main subject of the photo and was produced in an environment in which the man appeared to be familiar and relaxed (e.g. at home, in a pub garden, out walking). However, the context of, and meaning behind, each photograph was very different. Two women used their photographs to describe how cancer had caused a breakdown in communication which had almost led to a breakdown of their relationships, one woman used hers to illustrate cancer's impact on her body image and sexual relationship with her partner, one used hers to talk about her husband's support in comparison to the support given to friends with cancer by their husbands and partners and one used hers to explain the detrimental impact of her cancer on her husband.

Analysis audit trail

Symbolic interactionism and other interpretivist research paradigms emphasise research methods that are flexible and context sensitive as being the most effective for understanding complex issues involving human actors. However, this can make them difficult to evaluate for trustworthiness, truth and consistency (Mays and Pope 1995, Silverman 2000). In order to counteract such criticisms, many commentators have argued

that interpretivist researchers need to be reflective, able to challenge their own assumptions and recognise how their personal decisions have shaped the outcome of a study (Reid and Gough 2000, Koch 2006, Carcary 2009). Mays and Pope (1995) suggest that the basic strategies to ensure rigour in research employing qualitative methods is the same as that used when quantitative methods are employed, i.e. systematic and self-conscious research design, data collection, interpretation and communication and the goal should be to create an account which would enable another researcher to analyse the data in a similar way and come to essentially the same conclusion. It is generally advocated that this is achieved through the use of 'audit trails' (Lincoln and Guba 1985, Sandelowski 1986, Carcary 2009). An audit trail involves the systematic recording and presentation of information about the data gathered and procedures involved in a research project. It is a record of all the processes as well as the theoretical, methodological and analytical choices made by the researcher (Koch 2006, Bowen 2009). Although I have aimed to include such 'thick' descriptions of context, methodology and phenomena throughout this chapter and at other relevant points in my thesis (Bowen 2010), in appendix five I have also included a table presenting an example of a full coded interview transcript (table 14) and a table illustrating how a portion of the interview and photographic data was analysed to create the key theme 'reminders' (table 15) to demonstrate this further and as suggested by Lincoln and Guba (1985) and Bowen (2009).

Analysis workshop

As explained earlier in this chapter, I used an adapted photovoice technique in which interviews were conducted on an individual rather than group basis (Baker and Wang 2006). However, to retain the participatory emphasis and involve participants in the analysis of their own photographs as far as possible, I invited participants to attend one of two workshops that were held at the end of 2011 and facilitated by myself.

I applied for and was awarded some local University of Warwick funding which allowed me to hold two workshops with lunch and refreshments and reimburse participants' travel expenses. The workshops were held at the University of Warwick in Coventry and at the Ovarian Cancer Action offices in Camden, central London. These venues were offered free of charge and were fairly accessible to a large number of recruited participants.

I prepared a short presentation for the workshop which gave an update on the study and requested help from the attendees, which was to discuss as a group some of the photographs and the themes they appeared to represent, to ask attendees how they thought photographs should be interpreted drawing on their own experience and to put forward suggestions for categorisation of the photographs. I selected some photographs from the full sample which seemed to represent some recurrent themes and would not identify the people who had said they would attend and I prepared prints for us to view and discuss.

Five participants said they would attend the Coventry workshop and I sent reminders, maps and car park tickets a week before the meeting. Two participants sent apologies a day or two before the meeting (work commitments and a hospital appointment) and two did not turn up at the day, leaving just one attendee and myself. I held the workshop as planned, although there was obviously no 'group' participation! The attendee did offer a few suggestions as to appropriate names of the categories.

Six participants said they would attend the London workshop which was held a fortnight later. Fortunately all six turned up. I had hoped to be able to reflect on the first workshop and use it to re-evaluate the planning of the second one but this was impossible as it had not been a group event, so it was administered as originally planned. I did however

incorporate the suggestions of the Coventry attendee as a point of discussion. The attendees were all women and comprised one with an ovarian cancer diagnosis, one with an oral cancer diagnosis and four with oesophageal cancer diagnoses.

After the brief presentation, I shared prints of the selected photographs with the participants and tried to encourage a group discussion and interpretation, which I recorded. It was, however, difficult to maintain the intended discussion as participants began to discuss their personal experiences of cancer and seemed to seek support from each other. This was especially true of the four who had experienced oesophageal cancer as they began to swap advice and information specific to their side effects, for example to do with managing eating and their diet. If a photograph was presented that had been taken by one of the workshop participants, they claimed ownership and described its meaning from their perspective, which ostensibly vetoed any group discussion of its possible meaning.

It is probably unsurprising that the focus for these women was more on mutual support than any analysis of the photographs. It was the first time they had met and their commonality was living with and beyond a cancer diagnosis. Work describing relationships made in cancer support groups stress that they are based on a unique mutual understanding of the experience of cancer which complement but cannot be entirely replicated in the "taken for granted social world" (Ussher et al 2006, p2573). Ussher et al (2006) also describe some of the psychological theories that have been posited for the mechanisms of cancer support, including 'social comparison theory', in which the experience of comparing oneself with other people with cancer can validate feelings and normalise the illness, 'helper-therapy theory', whereby self-confidence and esteem are increased through the practice of helping others and 'narrative theory', where life stories

are constructed and identity is re-evaluated in a mutually supportive place. For example, Høybye et al (2005), showed how women with breast cancer gained empowerment through sharing their stories in an internet support group. This offered them recognition and had an impact on their well-being and rehabilitation. The Coventry workshop participant expressed disappointment when nobody else turned up as she said "I was looking forward to meeting other people and sharing my stories", therefore it is not inconceivable that the search for such support was what motivated people to attend the workshops.

Therefore, although the participants offered some useful thoughts on the interpretation of individual photographs and advice about the naming of themes (for example, the most appropriate coding for the many photographs and descriptions of pets by participants) which were incorporated into the final analysis, their input as far as the goals of the workshops were concerned were limited. However, I was able to discern, from the recorded discussion, some useful data about other aspects of living with and beyond cancer, which complemented the individual interviews. On reflection, it may have been more effective, although probably wholly impractical in terms of travel for the participants and funding, if I could have held a series of workshops so that groups could have got to know each other and formed relationships first, before becoming familiar with the photographs. It may also have helped if I had 'depersonalised' the photographs as much as possible by removing all those taken by the workshop participants as examples. In retrospect, it would also have been useful if participants had been involved in choosing representative photographs in which to illustrate themes at these workshops, to reduce any bias that might exist in the ones I have chosen (Rose 2007).

Dissemination of the study

So far, I have disseminated research results via newsletters, posters and talks to audiences which have included medical, nursing and allied health professional personnel, academics, health and social care policy makers, other patients and members of the public (see appendix six for full list). However, as previously discussed, photovoice is a participatory and empowering method and a main ethos of it is to involve participants directly in the dissemination of results (Wang and Burris 1997, Wang et al 1998, Hurman 2003). Such engagement is rarely reported or discussed in research reports (Catalani and Minkler 2010) but it has always been my intention to hold a participant-led exhibition of photographs in which professionals will be invited and study participants, either in attendance or via their own images contextualised by their associated narratives, will have the opportunity to feedback their experiences directly. Up until now, I have had difficulty in securing an appropriate gallery or community space which is not prohibitively expensive. Interestingly, although *all* the participants were happy to share their images and felt they should be seen, two venues expressed concern about the public nature of images about cancer and whether they might be upsetting to anyone who in inadvertently viewed them. This raises questions about the way in which boundaries are created between the portrayal of healthy and sick people (or 'self' and 'other') as discussed by Radley (2002). However, I have had an exhibition space accepted at this year's National Institute of Health Research INVOLVE Conference in Nottingham in November, representing public involvement in NHS, public health and social care research (http://www.profbriefings.co.uk/involve2012/index.html). Participants are welcome to attend, although the registration fees may be very prohibitive for many of them. As such, I intend to invite those participants who I know are alive and well to help me choose which photographs and associated narratives to display, so that they are offered as much involvement as possible in dissemination. In the meantime, I am

continuing to look for an appropriate location which will allow and encourage a more participatory event.

Conclusion

Recruiting via cancer charities and support organisations was much more successful and allowed a sufficient sample to be recruited in a realistic time-frame. However, recruiting in this way made it difficult to control for the representativeness of the sample. Although, the sample consisted of a good range of ages and there was a mix of cancers with poor prognoses represented, the sample was biased towards women, some of the poor prognostic cancer sites were not or were poorly represented, there was little ethnic diversity and the median age of participants was younger than the general population of people with cancer. Also, it is not known what motivated the participants to take part and whether the will to self-refer and be involved made them somehow different to those who did not. This sample is not necessarily typical. However, the recruitment strategy was productive and practical and the participants represented here may offer an insight into the experience of living with and beyond a poor prognostic cancer.

The participants generously created and shared a huge amount of data, the majority of which was of good quality and usable. Although Oliffe et al's (2008) modified method of layered analysis was straightforward to follow and apply, the coding of the photographs and associated narrative into representative key themes was a long, meticulous and repetitive process (see illustrative tables 14 and 15 in appendix 5). I had hoped to involve participants more in the analysis of their own data but this process had not been as successful as I had hoped, resulting in the analysis being fundamentally researcher-led. In the next chapter I present the key themes that arose from the participants' photographs and interviews.

Chapter 8

Principal study 'Living With And Beyond Cancer':

Results

Introduction

As explained in chapter seven, analysis was a long, iterative process using a 'layered approach' as conceived by Dowdall and Golden (1989) and modified by Oliffe et al (2008). Emerging categories were gradually refined and cross-referenced throughout the data gathering period and completed with a final and very thorough scrutiny once all the interview data had been transcribed and loaded onto the qualitative analysis software package NVivo8 and the associated photos had been printed. In this chapter I will describe the key themes that emerged from the visual and verbal narratives and illustrate them with related photographs and text. I will discuss my results in relation to other research findings and theory.

Codes and key themes

I initially identified thirty five different codes from the interviews and photographic data. Occasionally there were topics that were talked about during the first interview but were absent from the photographs or subjects that were photographed and discussed in the second interview but not mentioned in the first. These anomalies are discussed later in this chapter. Through a process of constant refinement of evolving themes and associated codes (see appendix five for detailed examples in tables 14 and 15), I identified six important distinct but inter-related key themes. The original codes and resulting key themes are illustrated in table 12 overleaf; 'The identification of codes and development of key themes to describe living with and beyond cancer'.

Table 12: The identification of codes and development of key themes to describe living with and beyond cancer.

	Codes from interview 1	Codes from interview 2 (photographs)	Key theme
1	Keeping healthy Physical appearance "Soldiering on" Side effects Limitations Loss of belief in self Loss of independence	Keeping healthy Physical appearance "Soldiering on" Side effects Limitations Loss of belief in self Loss of independence	**A "new normal"**
2	Looking towards the future Giving back Positive things about a diagnosis	Looking towards the future Giving back Goals and milestones Moving on	**Looking toward the future**
3	Damocles' sword Financial cost Constant reminders 'Club' membership The ambiguity of 'surviving'	Damocles' sword Financial cost Constant reminders Appointments & follow ups	**Reminders**
4	New perspectives Spirituality	New perspectives Spirituality The 'great outdoors' Appreciation My space	**A greater appreciation**
5	The effects on family & friends Loss of family or friends Loss of social contact Guilt Communication	The effects on family & friends Loss of family or friends Loss of social contact Guilt Gratitude Support	**The involvement of friends and family**
6	Why me? Rollercoaster "Fitting the box" Becoming a patient	Why me? Rollercoaster	**Why me?**

Description of the key themes produced

A "new normal"

"Our new normal" (6.2) was the way one participant described this category which represents getting back to a familiar routine after a cancer diagnosis and treatment but needing to incorporate a changed self or new way of being. Carrying on with a 'normal life',

as in engaging with the usual economic, social and relational realities that occur outside of illness (Thomsen et al 2011) and not allowing cancer to have a detrimental effect on daily life was a very important aspect of living with and beyond cancer for the study participants and has been identified by other researchers who have explored the experiences of people with cancer (for example, Auchincloss 1995, Mathieson and Stam 1995, O'Baugh et al 2003, Hubbard et al 2010, Maher and De Vries 2011, Thomsen et al 2011, McCaughn et al 2012). It is also described by analysts of biographically informed perspectives of chronic illness, such as Michael Bury and Kathy Charmaz (Bury 1982, Charmaz 1983, Hubbard et al 2010). Bury (1982) explains how his participants with RA had to consciously mobilise resources to maintain normal activities. However, the frustration and fatigue that this could cause often made people pare down their social activities, ultimately leading to further isolation. Similarly in my study, participants were keen to return to normal as quickly and thoroughly as possible after treatment, however the majority found that their 'normality' had been altered by the experience and the legacy of cancer and life had to be closely managed in order to incorporate increased fatigue and other changes (see figure 10; fatigue) and activities which were once routine and unproblematic sometimes had to be curtailed or supervised (see figure 11; menu). This was also noted by Thomsen et al (2011, p262) in their Danish population of people receiving palliative or supportive care. They found that although 'carrying on a normal life' gave security and meaning and was felt to be a very important part of what they termed being 'a participant in one's own life', it also entailed a significant degree of organisation because people had to manage with less energy and anxiety when people had to ask for help.

Figure 10; fatigue:

A battery is the fatigue, which is part of the side effects from the surgery I suppose … the fatigue has hit me hard … more so than anything else because that affects everything that you do and what you can manage to do in a day and I suppose in my head I still think I can do a lot of things but my body is telling me I can't but sometimes I've done it and by the end of the day I realise I've done too much (6.2)

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Figure 11; menu:

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The menu is about me going into restaurants before we book and asking to have a look at the menu to see if there are things on there that I can eat. Most big places have soup, so I usually end up just having a bowl of soup because if I'm with people I'm always worried about choking if I'm eating and not concentrating on swallowing, because if people talk to me it's a disaster. When you're in the social situation people forget and they ask you questions and then I'm desperately trying to swallow before I answer and so it's safer if I just have things like crème brulee where I know that I can swallow those things very, very easily … I do look at other people's plates and think gosh that looks good and I wish I could have that (2.2)

Side effects of cancer or its treatment lasted for far longer or were much more disruptive than participants had imagined they would be. Many participants of working age talked about and illustrated aspects of their working life or their attempts, sometimes unsuccessfully, to return to work (see figure 12 'getting back to work').

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Figure 12; getting back to work:

I felt quite a few times that my choice was either to stay in the house, pay my bills and not have any social life or somehow drag myself around to work … when you've signed up for the job or said that you're well or you're back at work and you've got over your transitional period, well then you're kind of on your own mate and you've got to take responsibility for your own health and you've got to explain to other people and if you really can't do it then it's just hard cheese, you just are going to have to accept that … it was only with hindsight that I thought it was ridiculous going back to work when I did (16.2)

Seven employed participants had returned to work after their treatment but had to retire or leave work completely because of long-term side effects even though many employers had put them on 'return to work' programmes or similar. These included two business women, a building site manager, two teachers, a social worker and a nurse. This brought financial concerns, social isolation and a threat to identity:

Whenever you go out to a social situation one of the first things people say is, "What do you do for a job?" Four years on I struggle with that because rightly or wrongly your identity is caught up in your status in terms of your work status, your marital status and all this kind of stuff and that builds up who you are as a person ... I don't want to say that I'm retired because I'm too young to be retired, so yes I still struggle with that (6.1).

A further three had had to reduce their working hours permanently and another three had changed their jobs within the companies they worked for to something less demanding. Only four had managed to eventually return to the same jobs and working patterns but

even this had not always brought security as they all described their reluctance to ever change their job because they would lose associated benefits (e.g. pension provision or life insurance), which they felt they would be unable to recover in a new post because of their medical history, or they felt that a new company would see them as completely unemployable. Others reported feeling isolated from their colleagues socially because of the break in their employment or because fatigue prevented them taking part in the extra-curricula aspects of work:

> Going back to work was tough actually. Being out of it for six months and people have done things and they've been together for six months and you haven't. I did feel quite isolated that I'd missed out on a lot of stuff through being off and I wasn't quite in the loop, you know. I used to sit at my desk and they'd be laughing and joking and I sort of felt a bit, I didn't share that bit and obviously I didn't go out after work. It was enough to get in to work and do the work and come home so I was missing out on quite a few social events and stuff. I did feel on the edge looking in at what they were talking about and doing, not able to really participate (26.1).

> In the classroom, especially working with disabled kids, if everybody's, you know, stressed out there isn't space for somebody who's not been well really (16.1).

As well as the obvious financial incentive, work has been shown to provide a structured routine, social support and to be of therapeutic value to people with cancer and is often a significant milestone for 'getting back to normal' (Ferrell et al 2003, Amir et al 2008). However, many researchers have reported that returning to a job held before a diagnosis of cancer or another chronic illness is not straightforward (Bury 1982, Richardson et al

2011). For example, Hubbard et al's (2010) study of people living their first year after colorectal cancer describes a lack of energy and concentration vetoing a return to old patterns of work. Similarly, some of Bury's (1982) sample of people with RA found it difficult to sustain work and, despite having managerial and union support, felt an informal intolerance from colleagues. As mirrored by participant sixteen, the chronically ill participants in the study by Charmaz (1983) found that managing work drained them of the energy needed for other social involvements leading to isolation. Fatigue is known to be the most commonly reported physical problem for long-term cancer survivors (Lawrence et al 2004), has the greatest impact on returning to work (Spelten et al 2003) and appears to be a significant factor in how severely people experience disruption (Reeve et al 2010). Significantly, many of my participants still talked about fatigue and its disruptive impact on the management of their lives even when they were recruited years after their cancer treatment. Long-term fatigue has been reported in populations with a 'good' prognosis, such as breast cancer, testicular cancer and Hodgkin's disease (Bower et al 2006); my study is the first to my knowledge that has described it specifically in people years after the diagnosis of a poor prognostic cancer. This is perhaps unsurprising as survival has been assumed to be very limited for these people. However, as two of my participants were recruited seventeen years after such a diagnosis and as so many were keen to return to paid work, it is an important factor and one which becomes more significant to both individuals and society in general as survival continues to increase (Bradley and Bednarek 2002).

Other 'new normals' included getting used to an altered appearance or new self-image. Some people had had to adjust to major and overt changes in their appearance and bodies, such as one woman who had lost the ability to sing after oesophageal cancer surgery or another whose tongue had been surgically removed (figure 13 'cheeky old face'). This had

not only altered her visibly but had also created a new, permanent and sometimes difficult to understand way of speaking, which was particularly problematical when speaking to strangers, increasing her sense of isolation.

Figure 13; cheeky old face

This is me with my cheeky old face and full tongue; relaxed, symmetrical, beautiful. I can never stick that out again ... It was a real emotional shock to look in the mirror and think, "Oh my god, new person, new face". I found that post-surgery and for the first sort of three years after surgery I found it very hard to have the confidence to even talk on the phone and it was, "Hi, I can't understand you; I'm hanging up". They wouldn't be very polite if I'd try and order a pizza or something ... It was a very brutal reception I got from most people (14.2)
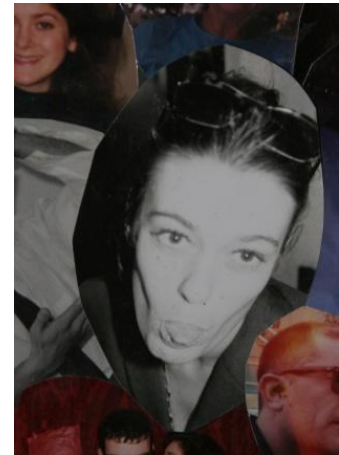
© A O'Donnell

Although an altered body image has been reported as a significant factor for people with cancer and is linked to a poor self-esteem, social anxiety and depression (Burt 1995, Colyer 1996, Bottomley 1997, White 2000) there has been little research that has explored this aspect as part of the 'new normal' for people who have had a cancer diagnosis. The literature that does exist has focused on 'visible' changes, such as those caused by surgery or chemotherapy induced alopecia (Harcourt and Frith 2008). My participants described a previously unexplored factor which was that less obvious or usually hidden changes in appearance also created an ongoing legacy for many participants (see figure 14 'people won't know'). In a similar way to Ferrel et al's (2003) women with ovarian cancer, these changes in appearance sometimes caused a lasting fear of intimacy, particularly for participants who were not in relationships:

I'm very worried about ever having a sexual relationship again because I do feel that I'm really unattractive ... I kind of think I'll never do that again and that makes me very sad (18.2).

Figure 14; people won't know:

There's nothing there that suggests I'm any different from anybody else, so day-to-day people won't know whatever has happened and obviously the reality is that underneath that you live with the legacy of what has happened to you. That's the physical side but of course there are bits in your head as well so although you look fine and inside even in your head it's still going on and a lot of people, even close people who should know better, don't always realise that, that it's ongoing even though you're well. (4.2)

Furthermore, participants detailed unwanted indirect physical changes caused by cancer treatment, such skin dryness and osteoporosis associated with a chemical or surgical menopause (Auchincloss 1995) or being thinner due to post-surgical digestive problems:

By being the size I am, you'll get comments. I had one last week. I was at a church thingy and there was tea and cakes, tea and biscuits and there was one cake left and one of the women said, "I think you need to be fattened up a bit". So people don't understand why I'm a size 6. It's not out of choice (6.2).

This meant adjusting to an unexpected 'new normal' which participants had often not been warned about or taken on board because of the more immediate cancer-related concerns.

In line with people with cancer in studies by Mathieson and Stam (1995), Hubbard et al (2010) and Hubbard and Forbat (2011), others reported looking or feeling prematurely old:

> It was a big shock for me, it was like suddenly being twenty years older, you know,
>
> Having to lose so much all at once so suddenly, that was really hard to adjust to
>
> (16.1).

I have also included changes that had to be made in participants' homes and environments to this altered self-image and code of 'physical appearance' as it seemed to affect their identity and self-esteem in a similar detrimental way and was part of the 'new normal' of visible difference. This was often mentioned but has not been identified in other studies of living with cancer and may have been prompted by the personal use of cameras in participants' homes. For example, one gentleman who had to buy toilet rolls in bulk due to long-term bowel problems but had to store them openly due to the small size of his flat took photos of them to explain his humiliation about this and three people with oesophageal cancer talked about having to sleep in a bed with a raised head and the embarrassment of having visitors see that bed. Another woman disliked her necessary but unwelcome surgical pillow which, she felt, spoiled her bedroom (see figure 15 'my bedroom'):

Figure 15; my bedroom:

I love my bedroom. Absolutely love my bedroom … then this is my surgical pillow. I thought of all the trouble I went to do the interior design and everything for this room and how lovely it looks because of all the beams and so on and then I've got this blooming surgical pillow which, because of my lymphoedema, I have to have. I have to use that to sleep because of my reconstruction and everything … so it's quite poignant again. It's my beautifully designed bedroom which I'm proud as punch of and yet it's got to have a surgical pillow put in there (30.2)

Looking towards the future

Initially, a cancer diagnosis seemed to take away the future for participants. As one woman described:

> It does remove your future and it's odd how that affects your mind when you don't think you have a future because everything you do, you're always kind of looking ahead to your holiday or Christmas or somebody's birthday and suddenly that goes. It's like you've lost an anchor because all of those things in the future are your anchors and you kind of move from one to the next and suddenly your timeline has gone and you don't know if you can make it to that next one (13.1).

This arresting of the future has been noted by other researchers, such as Breadon (1997) in her phenomenological study of women living after a cancer diagnosis. Stacey, in her own account of experiencing cancer, describes how the shock of diagnosis not only produced a "rapid series of renarrativisations" but also highlighted the previously unrealised "extent to which all kinds of narratives had quietly structured my imagination previously" (Stacey 1997, p6).

As such, starting to make plans and having goals again seemed to be a very important part of recovery for participants and many described reaching goals with pride and gratitude (for example, figure 16 'the stairs'). They were wide ranging and often dependent on the time since diagnosis, for example starting with having enough hair after chemotherapy-induced alopecia to feel able to go out without a wig, regaining the ability and confidence to walk round a local park, reaching a next birthday (or celebrating someone else's with them) or having a weekend away with friends. As Charmaz (1983) observed in her sample of people with chronic illnesses, cars were often mentioned and seen as symbols of

independence. Participants were particularly pleased when they regained the confidence to drive again after surgery or had their licence returned, in the case illustrated after a diagnosis of brain cancer and treatment related seizure (see figure 17 'getting my licence back').

Figure 16; the stairs:

I also remember the first time that I got up the stairs because I think it was some weeks after I'd got home and it felt like such a huge achievement and I quite often think now as I go up and down stairs, you know, I remember when I couldn't go up and down these, so that's great (16.2)

Figure 17; getting my licence back:

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This picture is to do with getting my license back, when the license fell through the letterbox. Again it's such a warming feeling of getting your life back together (21.2)

As time went on and goals were achieved, participants made more ambitious plans, such as planning a holiday which would be taken months ahead rather than only taking last minute deals.

'Cure' in cancer is a concept often alluded to but never clearly defined. In a biomedical context, cure is usually described as five years of event-free survival (that is, with no recurrence or progression) (Drew 2003). As a result people who have had treatment for cancer often have regular appointments with their specialist clinical team for five years before being discharged from oncological follow-up. Thus, five years since diagnosis was often seen as the point at which participants perceived themselves to be 'all clear' from cancer and this was repeatedly mentioned as the most important milestone to reach. Many participants had delayed doing certain things they wanted to do, but which demanded commitment, until that point, for example getting themselves a pet. Some participants had brought forward life goals that preceded their diagnosis, which caused a certain sense of ambivalence about achieving them (see figure 18 'my car').

Figure 18; my car:

Its fab and I just feel so good when I'm driving it especially when I've got my sunglasses on, put the roof down and yes, it's wonderful but at the same time … I was always promised that for my 50th and I've got it now because we didn't think I'd make 50 so it's kind of, I love it to bits, but at the same time I look at it and I think that means, I'm quite worried about it because I'm 48 now so I'm thinking okay when I actually have my 50th birthday is that going to be it, is that the time that I'm supposed to go sort of thing? I wanted a SLK but now I've got it I think actually I don't want it because having it means I've got this prognosis, so maybe I don't want it (30.2).

As McKenzie and Crouch (2004) explain, achieving the status of a cancer 'survivor' may imply a resolution of suffering but my participants, as theirs, found that post treatment was a time of great uncertainty. Little et al (1998) describe this as 'cancer patientness' which is the persistent identification as a 'cancer patient' regardless of time since diagnosis and the presence or absence of disease. They describe this as a 'liminal state' and suggest it stays with people who have had cancer for the rest of their lives. They liken it to Frank's 'remission society' which he says is where people who are well but can never be considered cured live "in the world of the healthy even if always subject to expulsion" (Frank 1995, p9). Liminality originates from the Latin for threshold (Sibbett 2005) and Navon and Morag (2004) describe people as liminal when, as a result of declassification from one role or group (e.g. 'sick') without reclassification to another (e.g. 'healthy'), their characteristics are seen to conflict and be incompatible with culturally established norms and they perceive themselves as being trapped between them. Little et al (1998) describe two stages of liminality in the cancer experience; 'acute liminality' at diagnosis linked to immediate physical and existential threat and associated fear and 'sustained liminality' that begins to occur at some point during convalescence when independence is reasserted. They say that during this stage, people remain aware of their 'cancer patientness' and move between features of acute liminality to a near resolution, depending on medical news, symptoms, social support and many other features. Auchincloss (1995, p2119) describes, what she refers to as, the 'check-up anxiety' that brings people face to face with their 'cancer patientness' just before a follow-up appointment is due. This is also described by Frank in his account of his cancer experience: "Whenever my own medical tests require 'further investigation', the skin that covers over the memories of my first cancer bursts ... suddenly the pain of having cancer bears down on me again with all its indescribable weight. Each time I learn how close to the surface those memories remain" (Frank 1995, p136). Sibbert (2005), an art therapist with a diagnosis of leiomyosarcoma, concurs with this and, as she

had previously worked with people with a cancer diagnosis, also describes the professional liminality that she felt when attempting to return to work.

For many of my participants, 'looking toward the future' was linked to altruism and meant looking toward the future for other potential people with cancer too. There was a strong sense of obligation to 'give back' for many participants and use their experience or knowledge to help others. Many had organised or become involved in events to support linked cancer charities, volunteered to help other people with cancer either formally or through friends and informal networks or by becoming involved with the dissemination of information via the media or other means (figures 19 'raising awareness' and 20 'ambassador').

Figure 19; raising awareness:

I did a lot of awareness raising, you know, in magazines and that ... people don't know any of the symptoms of ovarian cancer and I didn't before I was diagnosed. We all know about breast cancer and we all know about cervical cancer but we didn't know about those fifty years ago. Although some people might be scared that they've got it when they haven't, awareness is the only thing we've got and it's quite frightening how many women are completely oblivious to it and completely ignorant about it (1.2).

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Me with my volunteer badge. Did I tell you I volunteer now? … I have gone on a regular basis to the clinics and I literally go up to people and say "Do you want to go for tea or coffee?" and then sat with them and talked with them … they seem to find it incredibly helpful just to talk. They say, "Well, if you've been through it as well it can't be so bad". So I thought I was quite a good ambassador for the team really because the whole multidisciplinary team are just so fantastic so I wanted to give something back to them as well because they're always incredibly busy (2.2)

This may have been more pronounced in this sample as a large proportion of them had been recruited through cancer organisations or support groups with which they were involved. However, the phenomenon has also been noted in other studies, for example in the study by Ferrell et al (2003) of the social concerns of women living with ovarian cancer and Yi and Zebrack (2010) in their study of young adults who have had cancer. Also, Seale (2002, p116) in his study of news stories about cancer in the English language press, found a common portrayal of 'cancer missionaries' who were people, often women, who had been through a cancer experience and were now educating, persuading or bearing witness to others.

Reminders

Linked to the key theme of 'looking towards the future' was the key theme of 'reminders'. These were the frequent day-to-day triggers that ensured that cancer was never far from participants' minds. They often led to a feeling that they would always be defined by their diagnosis and would never be able to put their experience behind them. As one woman described:

I didn't want cancer to define me as a person - that was something I went through -

but I think without realising it, it does a bit (26.1).

Many spoke of a 'Damocles' sword' hanging over them and a constant fear of recurrence.

One woman who had been given an ovarian cancer diagnosis ten years ago described it as a

"guerrilla fight" and continued:

I feel like if I am caught off guard it will sneak round the edges ... I'm always waiting

for it to come back, always. Whenever I say something now which is a plan for the

future, I always feel it's like touching wood (13.1).

Another woman who had been treated for oesophageal cancer three years ago said, "You

walk under a heavy load thinking if and when it's going to come back" (9.1). This fear of

recurrence sometimes caused people to put their lives on hold and prevented them from

doing things they wanted to. For example one participant talked of her apprehension about

her plans to leave her job and start a bed and breakfast business, another had not bid for

Olympic tickets and another two were too afraid to book holidays that were going to be

taken more than a few weeks into the future. As one asked, "Do you plan for the future in a

positive way or do you safeguard and not be brave enough to do certain things?" (14.1)

Some participants also described being constantly reminded by the perceptions of others

and expectations of society. For example, two participants described being frequently

reminded by what they described as incessant media coverage and three participants

talked about problems with getting travel insurance, sometimes preventing them taking

the holidays they would like to:

I had them all ticked off, a list of fifteen different companies. Not one of them

would insure me and then in the end one of the insurance companies put me onto

another one but in order for me to be insured to go away just for seventeen days

it's costing £1600. At that point I thought this is just a joke and I said, "But I'm well at the moment, I'm doing really well, I'm fitter probably now than I have been in two years". They said, "Yes but you're not even twelve months into remission so this is how much it's going to be; do you want it?" But that I feel further stigmatises the notion that you're going to drop dead ... it angers me that there are corporations out there that use that against you and make you feel, well make you feel completely isolated. I think it's a very isolating disease to have (24.1).

The difficulty in obtaining travel insurance is a known phenomenon for people who have had a cancer diagnosis in the past and charities such as Cancer Research UK and Macmillan Cancer Care offer advice on their websites but it has not been identified as stigmatising or isolating in previous literature as it has here.

Some felt that at five years post-diagnosis, which, as described above is the traditional time for clinical follow-up to cease (Drew 2003), they might start feeling more emancipated and be able to rid themselves of some reminders (for example, see figure 21 'my wardrobe').

Figure 21; my wardrobe:

To me my wardrobe is a regular woman's wardrobe, too many shoes and too much stuff all crammed in and there's my wig box and so that really sums it up, the reality that it is still there … I'm still within the five years and so I kind of thought, well I might need it (4.2)
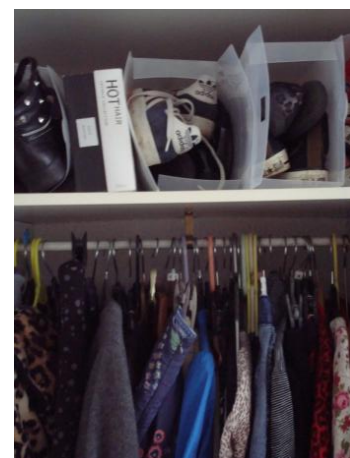
However, for those who had survived for longer, this did not appear to be the case, as one woman who had received treatment for ovarian cancer more than eight years earlier clarified:

> I carry on and I would have moved and got another job, but I don't think I'll ever – I will never presume again that I will still be here in two years, never again and most people in their forties do presume that they'll still be here in two years (1.2).

Another, who was living beyond oral cancer, explained:

> I still think in ten years' time I will always panic and I think you will always have that, I don't think you'll ever never have that, not have that fear because it's always there in the back of your mind, always (25.2).

Sometimes physical prompts acted as reminders. For example, five participants took photographs of the contents of bags showing items they now had to carry around with them, such as toothpaste and mouth wash to keep precious teeth clean after oral cancer treatment or spare pants in case of 'accidents' after oesophageal cancer treatment, which acted as constant and ever present reminders (see figure 22 'my bag').

Figure 22; my bag:

Oh gosh, we're onto the bag. I've got this huge bag full of stuff. Things you've got to remember ... I'm going on holiday abroad for the first time in five years. I must carry this kit wherever I go so that I don't worry about having a soiling accident, spare pants, wipes, buscopan. At least I've got less ambivalent about that because I had a phase of not carrying it around and then I had an accident of course, so I'm being very good. (16.2)

Corresponding with the participants with multiple myeloma in Maher and De Vries' (2011) study and Auchincloss's (1995) 'check-up anxiety' described above, imminent hospital follow-up appointments or waiting for cancer marker blood test results often prompted these reminders and made the experience more vivid and frightening for a period. Other participants even talked about the noise made by a digital thermometer, flowers that were in bloom at certain times of the year or views familiar at the time of treatment bringing it all back. For one participant, her home had become such a constant and distressing reminder that she was planning to move (see figure 23 'for sale board').

Figure 23; 'for sale' board:

That's a picture of my house with my for sale board ... That's my moving on I think and I feel like I need to ... It's kind of like I don't want to sit on that chair because that's where I sat. I don't want to watch those bulbs coming up because that's what happened and that's part of the cancer. I don't want to be in this house anymore (18.2)

Whereas increasing impairment and growing dependency exemplify many chronic illnesses (Tritter and Calnan 2002, McKenzie and Crouch 2004), the majority of my participants were typical of many people living with and beyond cancer in that they appeared well and independent. However, they lived with the possibility or probability of a recurrence at any time, with associated further acute treatment and/or death. This fear has been described in many other studies of people living beyond a cancer diagnosis (e.g. Auchincloss 1995, Breadon 1997, Lee-Jones et al 1997, Little et al 1998, McKenzie and Crouch 2004, Hansen and Tjørnhøj-Thomsen 2008, Armes et al 2009). In common with my participants, it is

reported to be very widespread and does not appear to dissipate over time (Johnson Vickberg 2003, Simard and Savard 2009). Furthermore, it seems to be the most prevalent psychological and social unmet need in those living beyond cancer (Thewes et al 2011). However, there has been criticism that the majority of studies investigating the phenomenon of fear of recurrence have focused on women with breast cancer (Richardson et al 2011); the features described may have been worse for my participants who had all received the diagnosis of a poor prognostic cancer and for whom the news of a recurrence may have been more expected.

Despite uncertainty being a feature of chronic illness generally (Bury 1982, Charmaz 1983), as McKenzie and Crouch (2004) describe, living with this specific and unceasing anxiety demarcates a group that are separate from people living with other chronic illnesses and makes 'cancer survivors' distinct from survivors of other traumas as the prospect of re-occurrence is frequently never far away. Maher and De Vries (2011) argue that maintaining a sense of normality becomes highly significant for people who are living with such constant uncertainty but, as Hansen and Tjørnhøj-Thomsen (2008) suggest, the unremitting fear of recurrence means that people who have had a cancer diagnosis will never truly get back to normal. This fear and uncertainty become part of 'cancer patientness' described by Little et al (1998) and explained above or, as Kleinman (1988) explains:

> Cancer is an unsettling reminder of the obdurate grain of unpredictability and uncertainty and injustice – value questions, all – in the human condition. Cancer forces us to confront our lack of control over our own or others' death. Cancer points up our failure to explain and master much in the world.
>
> Kleinman 1988, p20.

To offer an example of this, if participants used terms such as 'cancer survivor' or 'survivorship' during their interviews, I explored with them whether such descriptors were helpful. Although such terms are pervasive within society and established terms in research (McKenzie and Crouch 2004, Twombly 2004, Doll et al 2012) I did this because personal accounts and research have suggested that they may not be helpful (e.g. Sontag 1991, Ehrenreich 2001, Khan et al 2011[A]) and there has reportedly been a recent backlash from those living with the disease who do not necessarily identify with such terms (Twombly 2004, Khan et al 2011[A]). I was interested in whether they might isolate those for whom long-term survival is unlikely, as suggested by King (2006). Some participants were encouraged by the notion of survivorship and proud to call themselves survivors, for example:

> I'm really proud to be a survivor because I know people that haven't made it and the older you get, the more you value being a survivor (14.1).

> I think the chance of survival for a mouth cancer patient is slightly less than fifty percent but of course I was sixty-eight at the time and had one or two other medical problems. My chances were significantly lower than that, about thirty-five percent, so I see myself very much as a survivor (3.2).

However the majority did not like such expressions and, interestingly, the most common reason they gave was down to the constant fear of recurrence (Hansen and Tjørnhøj-Thomsen 2008) which made them feel they did not qualify for the status of a 'survivor':

> I'm always waiting for it to come back, always. I would only say I have survived it up until now. There would be a kind of caveat and a qualification (13.1).

I don't quite like this 'survivor' thing. I don't know what that is. I think kind of I have

this mental picture of a perfectly healthy person who's suddenly threatened with

death and then it's taken away but I don't feel like that (16.1).

I've never called myself [a survivor]. I don't know what I call myself but no, I've not

called myself that ... You know, you're on a bit of a plateau at the moment

and I'd like to think because it has been totally removed then it won't come back

but that has always worried me and it still worries me. I don't think it's just me but

I think that people who've had cancer are always looking over their shoulder

thinking when is it going to come back again (6.1).

Similar findings have been reported in a recent UK study of people who have lived for at

least five years after a diagnosis of breast, colorectal or prostate cancer (Khan et al 2011[B]).

A greater appreciation

Many participants talked about the experience of cancer giving them a different

perspective and increasing their enjoyment of life. The things people described as

appreciating more, or beginning to value when they had not before, included spending

time with important people, taking part in pastimes and hobbies and enjoying nature and

the 'great outdoors'. As one woman said:

I didn't realise how beautiful things were ... You know, like when a piece of Galaxy

melts in your mouth and you think that's really nice as opposed to it's just chocolate

(20.2).

For some, the experience of cancer had also taught them that some people and things were *less* significant and it was unimportant to spend time with them:

> If I now don't want to put my efforts into that relationship I now don't. You know, where sometimes somebody wants to see you or something and you think I don't really want to meet up with her but I will; now I think I'm not (18.1).

For others, cancer had given them the confidence or impetus (or time as they were no longer working) to try things they would not have before, such as going to places or on holidays they would not normally have considered or even managing the refurbishment of a boat (see figure 24 'new projects').

Figure 24; new project:

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A new project, new ideas, new beginnings and the fact that it's sort of new avenues opening up and new chances and opportunities that didn't really exist before and the courage to go & do them …. Before I had cancer I would have said "Oh no, get someone else to do it" ... but I said "OK, yes, why not? I'll do it" (7.2)

Some participants described "hidden silver linings" (7.2) such as losing weight or being able to manage things more easily (for example, figure 25 'container garden').

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Figure 25; container garden:

After treatment and everything and lymphoedema in my arm I can't garden the way that I used to. Now everything has to be in a container so that I can actually lift it up on to a table, dead-head it and sort it all out and then go and put it back and I can do them one at a time and I feel like it's manageable. Actually this now, as a container garden on my patio, is the best garden I've ever had. Which is ironic really when I say I can't garden anymore because of the restrictions, I've now got the best garden I've ever had in my life (30.2)

One participant illustrated her own experience of 'a greater appreciation' with the following photograph and explanation (see figure 26 'greater appreciation'):

Figure 26; greater appreciation:

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Out of the inanimate object you've got this beautiful living thing so I just thought the inanimate object can represent the cancer because it's sort of an alien thing really. I know it's a living growing thing but it is an alien body but out of it you've got an emergence of something quite beautiful and I think sometimes when you come through cancer, you just emerge in a slightly different way maybe. Good things come out of it (26.2)

This greater appreciation for life after cancer and other life-threatening illnesses, sometimes known as 'benefit finding' (Thambyrajah et al 2010) or 'post-traumatic growth' (Scrignaro et al 2011), has increasingly been reported over the last decade (Heffernon et al

2009). So far, the majority of information has been extrapolated from quantitative surveys, for example a greater appreciation has been identified in populations of people living after colorectal cancer (Jansen et al 2011), breast cancer (Mols et al 2009), ovarian cancer (Stewart et al 2001) and after cancer-related surgery (Schulz and Mohamed 2004). This study supports benefit finding after cancer and explores the subjective experience in far greater depth.

Frank (1995, p115) uses the term 'quest narrative' to describe such accounts of growth and greater appreciation after cancer and defines them as, "the ill person's belief that something is to be gained through the experience". Drew (2005), in her description of the narratives of people who have lived through childhood cancer, describes them as positive stories of challenge, resourcefulness and personal development. However, she has identified them in the narratives of people who experienced cancer while still babies or toddlers and, in asking how they could therefore know, deduces that they must be part of a cultural imperative that shapes and characterises cancer. This is noted by Ehrenreich (2001) writing about her own encounter with breast cancer: "In the breast cancer culture, cheerfulness is more or less mandatory, dissent a kind of treason" (Ehrenreich 2001, p50). McKenzie and Crouch (2004, p151) use the phrase 'relentless optimism' and King (2006, p101) uses the term 'the tyranny of cheerfulness' to describe these accounts of enrichment and suggest they are linked to a widespread belief that frustration, isolation and misery are linked to cancer and therefore to be cheerful and optimistic will aid recovery. O'Baugh et al (2003) and McKenzie and Crouch (2004) recognized a compulsion to remain positive in their participants although this required continued vigilance, self-control and censoring of communication in order to appear acceptable and also to protect people close to them from anxiety. As one of my participants said, "I've got so much anger and resentment and I feel so guilty because [my family] are very, very supportive but I feel like I've shut them

out" (9.1). O'Baugh et al (2003) also compared the perceptions of 'being positive' between people with cancer and their nurses and concluded that nurses perceptions could be very demanding on patients as they expected patients to be accepting and hopeful, look on the bright side, have a 'fighting spirit', take some control and participate in support groups. Being angry, overwhelmed, withdrawn or not believing in the treatment offered was seen as negative and unhelpful.

The involvement of friends and family

Of the thirty participants, eighteen included at least one photograph of, or representing, friends and/or family members who had been particularly supportive towards them when they were diagnosed with cancer and in the time since and they spoke of their extreme gratitude towards these people (for example, figures 27 'egg cups' and 28 'scaffold'):

Figure 27; egg cups:

It really makes me happy when I look at them because I remember [a colleague] and I had a lovely walk and found this shop that had all sorts of wondrous kitcheny things in and china things and she bought me this egg cup so that was like something really positive and nice coming out and it was so nice that she and my friend and my sister understand so well what the problems are or issues are and I don't have to explain myself all the time (16.2)

Figure 28; scaffold:

The scaffolding is like a strong supporting thing which is how I felt during the disease that I was very well supported by the hospital, by my family, by my friends. So that's the strength of the sort of scaffolding. Then the ladder, which is still there I think, yes, the ladder is like the support that helps you to move on, basically, so you can sort of start to make some progress. That does reflect how I did feel that I was supported a lot and you know … this is going up into, well who knows where because there is no end to this picture, it's taking you on and step by step you can make progress (26.2).

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It is now widely recognised that social support and affiliations have powerful effects on both physical and mental health and wellbeing and are beneficial in helping individuals adjust to stressful events, such as a cancer diagnosis (Flanagan and Holmes 2000). 'Social togetherness' (Thomsen et al 2011, p262) or having others 'sharing the journey' (Breaden 1997, p982) is reported as being very important for people with cancer and for some participants cancer was construed as bringing families closer:

> I think too because of what's happened we're probably closer than we would have been otherwise ... I think perhaps what's happened has bonded us and cemented us together in a way that if I'd been healthy throughout, probably wouldn't have happened (12.2).

However, Bury (1982) and Charmaz (1983) describe chronic illness as altering the usual expectations of reciprocity and mutual support between the individual, their families and social networks and how this can force changes in role and identity. Although not specifically depicted in photographs, other participants recognised this and the disruption

that it could potentially cause. For example, some talked about friends or partners having to do "all the fetching and carrying" (12.1) when they were unable to, one participant's wife had had to learn to drive as he was now unable to, others described their children having to grow up quickly and how they may have missed out on the usual things associated with young adults and one woman felt that her friends and family were probably unable to express their own concerns in front of her because they felt she always had it worse. Some people felt very guilty about the effect of their cancer on family and friends. Three women described deliberately organising people to take their partners out so that they would be able to have "time out from the whole cancer thing" (24.1). In line with McKenzie and Crouch's (2004, p149) respondents who described themselves as 'emotional carers', many of my participants avoided talking about cancer or downplayed its impact to family and friends. Some withheld information from, for example, elderly parents, even if this had increased their own feelings of isolation:

> I've not told anybody other than myself that my scan is on 28th June. My parents, they are in their seventies and I just think it's putting pressure on other people. I don't think they need to have that pressure just at the moment ... there is no point putting them in the loop of worry. I just stop in the loop by myself. I'm going round the track of worry and then when I've had it done I can say "it was fine" or "it was this" sort of thing ... I'm not trying to be nasty or telling people lies and things like that. I think it's just trying to keep the weight off other people's shoulders because I don't think it needs to be a known thing really straight away. I'd rather let their lives carry on as they can and mine carry on as mine can really (21.2).

Gratitude for support received was occasionally tempered by a certain ambivalence caused by feelings of separation and being outside the social sphere (see figure 29 'daisy chain').

Two participants had taken photographs of their family or friends but one had photographed them from behind and the other had ' blurred' them until they became unrecognisable to indicate their presence but their inability to completely understand the experience. Two women spoke of coming very close to getting divorced after their initial treatment which they believed was solely due to this separation and the ensuing communication difficulties between them and their husbands.

Figure 29; daisy chain:

I chose the daisy chain because when you link them together they do actually make a very strong link ... this is a support network of the chain around me in the middle ... even once I'd sort of come through chemo the support was still there and I was still in the middle being helped and stuff like that ...

... and then in conjunction with that I've got the daisy chain again but me on the outside because I did sort of feel that having had the experience of going through the cancer journey it does place you outside other people's sort of experience really. I did feel a bit left out in certain things because I missed out on not being at work, not being able to socialise fully (26.2).

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Similar conflicts have been identified in other studies. For example, 'social support' was the most dominant key theme for women with ovarian cancer in the study by Ferrell et al (2003) but the generosity and support that their women were so grateful for did not resolve the overwhelming isolation they felt in being alone with their cancer. Furthermore, their participants described the new responsibilities, restrictions and fears that 'burdened their families' and the 'extraordinarily difficult' challenges that ovarian cancer had brought to relationships with partners. Similarly, the participants receiving palliative care in

Thomsen et al's (2011) study describe the security and loyalty they receive from family and friends but also the fragility of these relationships.

Flanagan and Holmes (2000) have explored the literature on the impact of cancer on social relationships and draw on the construct of stigma to explain avoidance behaviour in the experience of cancer. Goffman's early work on stigma has been very influential in the study of chronic illness and the labels that are attached to it (Goffman 1963, Nettleton 1995, Weiss et al 2006, Blaxter 2010). Goffman (1963) describes stigma as occurring when there is a discrepancy between stereotyped social identity and actual social identity and a process by which the reaction of others damages identity. He says that the degree of stigma that an individual experiences will be dependent on four variables:

- Visibility – the extent to which signs and symptoms are recognised by others

- Awareness – the extent to which others know about the illness

- Obtrusiveness – the extent to which usual interaction is hindered by the illness

- Perceived focus – the perception of others about the individual's ability to participate fully.

Susan Sontag (1991) was probably the first author to examine the relevance of stigma on cancer in her own account of the illness and personal accounts published since have endorsed this (e.g. Stacey 1997, Picardie 1998). As Stacey (1997, p67) explains:

Don't upset this friend or relative, hide it at work, keep it from your children. The cultural imperatives of secrecy and disguise are a constant reminder of the price of living with a stigmatised disease.

Stigma has also been identified in research studies and appears to be particularly felt by people who are thought to be responsible for their illness, such as lung cancer (Butts Stahly 1988, Fife and Wright 2000, Chapple et al 2004, Hansen and Tjørnhøj-Thomsen 2008, Else-Quest et al 2009, Gonzalez and Jacobsen 2012). I suggest this indicates that a fifth, cancer-specific, variable of 'perceived responsibility' may be at play.

Stigma may be 'enacted' or 'felt'. Enacted stigma refers to actual discrimination, whereas felt stigma refers to the perceived shame an individual has about their illness and the fear of being discriminated against because of its social unacceptability (Nettleton 1995, Chapple et al 2004). Participants reported experiencing both within their support networks. For example, this woman reported enacted stigma from work colleagues:

> I've been really shocked to have this sort of broader view from a lot of people about what cancer means to them and it's like being a leper. It's only my close friends who have been amazingly supportive ... I just feel completely maligned, stigmatised by having this condition and that is something that I didn't expect at all (24.1).

Others described keeping things from others due to felt stigma:

> If there were people that didn't know and didn't need to know I didn't tell them because I didn't want those reactions. I kind of felt that when people knew then they reacted to me slightly differently and I didn't want to be that person over there with cancer (13.1)

Furthermore, some participants, particularly those who lived alone, often spoke about the possibility of meeting future partners, the difficulty of how and when to tell people and the

stigmatising effect a history of cancer may have on a new relationship. Two women had been left by prospective partners when they told them about their previous diagnosis; one being told it was because she "didn't have a very good life expectancy" (7.2) and another asked:

Do you tell somebody you've had it because people do think if you've had it you're going to get it back again, don't they? People, the world, thinks that if you've had cancer you will probably get it back again, that is a world feeling, isn't it? (18.1)

Seven participants had included photographs of their pets which I and the participants attending the analysis workshops (see chapter 7) agreed should be included under the key theme of friends and family because they were frequently described as 'members of the family.. Domestic animals appeared to serve many purposes, including bringing "joy, laughter and love" (24.2), causing participants to relax "just watching the animals do their thing" (21.2), being "something normal and treating you the same" when everything else was unusual (11.2), being "very therapeutic when you're going through something like that and you're feeling ill" (30.2) and "keeping me going, keeping me fit and active" (12.2) (see figures 30 'the animals').

Figure 30: the animals

They amused and entertained me while I was in bed while I was ill and couldn't get out and do much and they keep me busy now, having to go out every day and things and that's why I put them in really. They assumed quite a big part because obviously the family were wonderful, but obviously they have to go to work but the animals are there day in and day out, you know. They are entertaining and amusing and they keep your spirits up (12.)
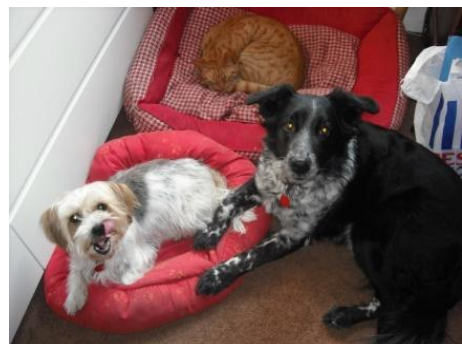
Although there does not appear to be any relevant literature on the therapeutic value of pets for people with cancer, there is some evidence that suggests pets may alleviate depression and offer companionship and emotional support when people are ill (Edney 1995, Wells 2007).

Why me?

This theme does not refer to resentment or feeling sorry for oneself but more to a sense of confusion that many participants had felt at diagnosis and which often remained with them because they did not think they fitted the stereotype of the 'type' of person who should have had their diagnosis or, sometimes, any diagnosis of cancer. Most had asked themselves or medical staff, "why me?" but had not found or been given answers they thought suitable or rational and there was a disparity between the public health message and their perception of their lifestyle and behaviour (see figure 31 'healthy food').

Figure 31; healthy food:

I don't understand why I've got cancer because I eat broccoli and tomatoes and they're supposed to be anti-oxidant and tomatoes have got something in them and it didn't make any difference. I think I was a little bit sort of peeved and angry that I'd been doing everything I was supposed to do and it didn't stop it happening … I've got water droplets on it so it could reflect like tears of frustration or that, you know, I tried to do the right thing and eat the right foods and it still didn't work so little droplets of water ... a few splatters of water just to show a little bit of sadness or frustration that that happened (26.2).

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Some were left with a feeling of being culpable for their diagnosis and wondered if they had done something wrong to justify it:

> You're working out, "what have I done wrong, why have I got it, what happened?" You have to have a reason don't you? … I think when you have that sort of traumatic diagnosis it has a "what happened and why have I got it?" I was self-blaming. You know, "was I responsible?" (14.1).

Or anger because they had led morally respectable lives and did not feel they deserved it or should have been "challenged" by it:

> I've always looked after myself properly and everything so it kind of felt unjust and I don't know why I had it. I don't know why I was challenged to have it because my husband went off with somebody fifteen years younger than me, left me with three children. I raised those three children (18.1).

Many participants reported having to justify themselves to others, including sometimes their own family and healthcare staff, who, they felt, judged them by their diagnosis. One woman justified her own diagnosis by looking to other 'good' people:

> You kind of feel like I can't be a terribly bad person because that person has got it and that person and they're not terribly bad people so no, I did find that helped (13.1).

The rationalization of their diagnoses was often very pervasive. Although some people had come to the conclusion that cancer was arbitrary and it was as relevant to ask "why not me?" (30.1) (and see figure 38 'feather'), others were still searching for a reason years after their diagnosis. The only reason that any participants had produced was to be a mouthpiece for cancer awareness:

It happened because maybe I'm a strong person and I had to do this work to raise awareness within people and I think within the [Asian] community cancer is something they think that they're going to catch (10.1).

I think it was because I was strong enough to fight it and I've been helping since I've got diagnosed, I've been helping. I've been doing my research, I've been doing articles about mouth cancer and I think if another person may have had it they may not have been strong enough to do it (25.2).

Figure 32; feather:

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I was also quite strong at the time when I was obviously diagnosed and the feather was like well you can be as strong as you like but you can be knocked sideways and the feather, even something as light as a feather, can just knock you sideways basically. There's a phrase isn't there, knock you down with a feather? No matter how strong you are the unexpected can happen and whoosh, you know, suddenly you are in a completely different place ... I am strong, I am fit but you've still got that feather that can knock you down (26.2)

Stacey (1997) and Crawford (2000) suggest that there has been a widespread shift in the West during the second half of the twentieth century towards the principle that remaining healthy is an individual duty. This is perpetuated within and through biomedical circles, government policy and the philosophy behind complementary therapy (Stacey 1997, Fitzpatrick 2001). Indeed, from their extensive interviews in France, Herzlich and Pierret (1987) identified a changing view from passivity and deference to medical practice in the 1960s to responsibility and motivation to remain healthy in the 1980s. Crawford (2000) and Fitzpatrick (2001) argue that contemporary society has redefined health from its traditional

focus on treating illness and disease to the way in which lives are led. As Crawford (2000) explains:

> Health has become a key marker of identity and well-being – a code for signifying persons, qualities, moral capabilities and situations. Health reveals the truth of a body that 'cannot lie' and continues to provide one of modernity's most effective 'natural alibis' for masking the politically protected privileges of class, race and gender. In the body's health we search for and find confirmation of a life well lived or lived poorly, a nature within that discloses through signs and symptoms individual biographies and social trajectories.
>
> Crawford 2000, p225.

Furthermore, Herzlich and Pierret (1987, p62) suggest that cancer incorporates this discourse of individual responsibility and virtuosity more readily than any other disease:

> Cancer is the illness of individuals in their relations with society. It is indeed the illness of the individual but this individual can only be conceived of in relation with society as a whole. At the same time cancer is also an illness produced by society but one that manifests the flaws of the present-day individual.

The message about cancer and prevention is definitely persuasive and often linked in the media to issues of morality and responsibility (Seale 2001[A]). However, it is not always easy to comprehend, as illustrated in the somewhat confusing diagram taken from the Cancer Research UK website and entitled 'The causes of cancer you can control' (figure 33). This represents the results of a recent study, widely reported in the British media, about the lifestyle and environmental factors relevant to cancer causation (Parkin 2011, Cancer Research UK[A] 2011). Health promotion assumes a distinction between 'consumers' with

needs, wants and desires and 'providers' with plans, targets and goals but it may be naive to believe that individuals' actions are motivated solely by considerations of health without acknowledging the complexities of cultural obligations, reasoning and power negotiations (Naidoo and Wills 1994, Nettleton 1997, Petersen 1997, Gabe and Calnan 2000, Henderson and Petersen 2002).

Figure 33: 'The causes of cancer you can control' (Cancer Research UK 2011[A])

As shown in my literature review (chapter three), the lay understanding of cancer causation is complex and ambiguous. There is often a stereotypical view of sedentary, poorly-educated people, 'worriers' or those who eat 'unhealthy' diets as being most likely to develop cancer and people expect that they can exert some control over their cancer risk through avoiding certain lifestyle choices. However, when people know of individuals with cancer who do not fit the stereotype, it causes confusion. This is certainly true for the participants in my study who showed bewilderment or anger when they could not identify a cause:

> In some respects I think it might have been easier had I fitted a box. If I could have held my hand up and said, "Yes I smoke" or "Yes I did that twenty years ago and I'm now paying the price" ... it didn't really all add up and I suppose I could have squared it up better if there was something about my diet or my lifestyle that I could say, "Yes actually that is something I've done and it's now coming back and I've got to deal with the consequences" (6.1)

This fits with Goffman's dramaturgical self-construction explained in chapter one in which he argues that, from a symbolic interaction perspective, individuals strive to convey an identity consistent with expectations formed by an audience (Goffman 1959, Robinson 2007). Asking "why me?" appears to be common in people diagnosed with cancer (Ferrucci et al 2011). Furthermore, quantitative research has reported that the causal attributions that individuals ascribe to their cancer diagnosis can affect their quality of life, psychological and social adjustment and distress levels (Ferucci et al 2011). Writers who have written about their own experience, such as Sontag (1991) and Stacey (1997), describe the persuasive paradigm that makes individuals' feel responsible for their own cancer (and recovery) and the punishing metaphors that are associated with this. For

example, Stacey (1997) recounts her meeting with a professional who tells her of his own experience:

> Did I know why I had cancer? He knew why he had 'his cancer'. His parents had been unable to really love him. His school had been barbaric. The distress had accumulated. 'His cancer' had revealed all this to the world and indeed to himself. What did I think 'mine' was trying to tell me? He tries another tack. Was I afraid of self-exploration? Sometimes you have to go right into the depths of despair before you can surface anew (be reborn?) I could do things differently now and stay healthy. It is my choice. Do I really have no idea why I had cancer? Am I willing to take the risk, to seize the opportunity, to receive the gift? It's not a question of blame but of cause and effect, of responsibility.

Stacey 1997, p202.

Missing photographs: similarity and difference in words and images

The participants and I took part in two interviews about their experience; one prior to taking the photographs and one after and about the photographs. I would argue that there was surprising congruence between the points covered in each interview and the themes that emerged from them. However, there were some differences as illustrated in table 13: 'Codes emerging in one interview only'.

Arguably, the codes that emerged from the interviews only but were *not* photographed were more to do with existential concerns or were abstract concepts and therefore probably less easy to visualise and produce in a photograph. Similarly, the codes that appeared in the photographs but were not mentioned in the initial interviews were usually of more specific and tangible items.

I will explain this here using the example of the key theme 'reminders'. The photographs that appeared independently in this category were coded 'appointments and follow-ups' and included three photographs from three different participants of:

- A blood form for an upcoming CA125 (ovarian cancer marker) test to illustrate the 'reminder' of living with constant disease monitoring

- A montage of hospital appointment letters to illustrate the 'reminder' of having to incorporate frequent hospital follow-up visits into life

- An assortment of envelopes containing correspondence related to appointments and meetings with a participant's workplace, trade union and solicitor to demonstrate having to deal with what he felt was constructive dismissal from his work due to his cancer and how this was a constant 'reminder' of his diagnosis to him.

These all showed physical items which had to be dealt with and which sat on participants' tables or kitchen workshops as concrete reminders of their cancer. They were easy to photograph but also poignantly illustrated the theme. (I have not reproduced them here as they all show participants' names and addresses). However, participants also talked about 'club membership' and the 'ambiguity of surviving' which I coded as 'reminders' but which did not have any photographic representation. Examples are replicated in the following interview extracts:

It's as if you become a member of a club that you didn't ask to join; it's exactly like that (26.1).

Obviously primary diagnosis I understand is a very different ball game but when you are secondary you have been dealt this hand and you have to deal with it and you don't get a choice as to whether you want to be a survivor. I don't consider I am a survivor because I know I am reminded all the time that I am not going to survive but

on the other hand I am here, I am smiling and so therefore maybe I am, maybe I am a

survivor. It is really difficult isn't it? (30.1).

As concepts, these are probably less easy to embody in a photograph and were therefore

absent codes in the second interviews, although this does not necessarily diminish their

significance.

Furthermore, there were other codes that were present in large numbers of photographs

but absent from initial interviews, such as photographs of family, friends, colleagues and

pets to signify the code 'support' under the key theme 'the involvement of friends and

family' or photographs to illustrate the code 'the great outdoors' (examples in figure 34

'the great outdoors) for the key theme 'a greater appreciation'.

Figure 34; the great outdoors

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As discussed in chapter four, there are certain conventions at play when people take personal photographs (Van Dijck 2008, Pink 2011, Van House 2011) which should be recognised as they may have the potential to influence the photographs created. For example, photos of family and friends and tourism and travel seem to stand out as dominant themes for amateur or 'everyday' photographers (Sontag 1979, Harrison 2002[A], Van House 2011) and this has been revealed in photo-interviewing studies that have employed quantitative content analysis (Einarsdottir 2005, Lassetter et al 2007, Rampton et al 2007). Furthermore, and in line with models of symbolic interactionism, humans adopt roles to construct self-identity they deem appropriate to their audiences' expectations (Goffman 1959, Robinson 2007). Photographs are therefore created for an audience and may be used as both a memory tool and a way of communicating and sharing experience (Van Dijk 2008, Van House 2011). As such, they can be used to present a self-image or self-perception as well as a straightforward story or experience. Both Guillemin and Drew (2010) and Radley (2010) give examples of people who are ill but only wanted to present positive pictures of themselves which held pleasant memories.

For this reason, and considering the 'culture of cheerfulness' that exists around cancer discussed above (Ehrenreich 2001, O'Baugh et al 2003, McKenzie and Crouch 2004, King 2006), I would argue that the preponderance of photographs illustrating, for example, 'support' may not simply be due to this being the most important element in participants' minds. There appears to be no question that participants felt truly grateful for the support they had received and love towards those who had given it but their interviews often exposed contradictions and ambiguities that their diagnosis had brought to relationships. The large number of such photographs may, instead, reveal what people are used to and feel comfortable (or perhaps feel expected) to take photographs of. They were presenting not only their story but also themselves to me as the researcher and, in giving consent for

their photographs to be used in publications and presentations, perhaps to the wider world as well. As one woman admitted:

> Some bits of it felt very positive you know, like taking a picture of people, especially all the people, it felt like saying a little sort of thank you to them and that was very nice (16.2).

Table 13: Codes that appeared in only one interview and associated key themes.

	Codes from interview 1	Codes from interview 2 (photographs)	Key theme
2	Positive things about a diagnosis	Goals and milestones Moving on	Looking toward the future
3	'Club' membership The ambiguity of 'surviving'	Appointments & follow ups	Reminders
4		The 'great outdoors' Appreciation My space	A greater appreciation
5	Communication	Gratitude Support	The involvement of friends and family
6	"Fitting the box" Becoming a patient		Why me?

Conclusion

In this chapter I have presented and discussed the results of my principal study and also examined the anomalies that have sometimes occurred between what participants took photographs of and what they said. The six discrete but related key themes identified from the participants' photographs and interview narratives have highlighted aspects of the experience of living with and beyond the diagnosis of a poor prognostic cancer for the first time. They reveal that living with and beyond cancer is a persistently disruptive and liminal experience that continues long after people are discharged from cancer 'follow-up' and prevents them defining themselves as 'survivors'. Their experience is also often complicated by the social response and stigma associated with cancer (Tritter and Calnan

2002). The results of this study augment and enhance the very little subjective knowledge

so far available about people who are living after a poor prognostic cancer diagnosis and

add the perspectives of a previously under researched group. They also highlight potential

areas of further research and implications for care, which are discussed in chapter ten.

Furthermore, the photographs produced by the participants to illustrate and explain their

experience have added a poignancy and 'completeness' to the data which has arguably led

to a more comprehensive understanding. The key findings of the study and the potential of

the participant-produced photographs are discussed in chapter nine.

Chapter Nine

Discussion

Introduction

The purpose of this chapter is to present and discuss the key findings derived from my main empirical study. I will also consider their practical application and I will relate them to my study questions and theoretical approach (symbolic interactionism).

Key study findings and relationship to research questions

In précis, the key study findings of my main empirical study are:

- Living with and beyond cancer is an ongoing process that continues well past the point of a biomedically defined 'cure' and may be exacerbated by the status cancer holds in society

- Participant-produced photographs, used here for the first time specifically in a sample of people with a poor prognosis cancer, have proven to be a straightforward method of data collection for participants and have added to the richness of the interview data produced

- Images presented with associated narrative offer a powerful means of communicating the experience of individuals.

Each finding is discussed more fully below and related to the original study questions.

While focusing on the broad question of:

Living with and beyond cancer is an ongoing process

My main study question was, "what is it like to live with and beyond a diagnosis of an expected poor-prognostic cancer in a society that celebrates survival?" and the results of this study clearly show that, for this group, living with and beyond cancer is an enduringly

disruptive process that can continue long after they are discharged from specialist cancer care (usually at five years post diagnosis).

My study is unique in that it has recruited people who have survived both up to and beyond five years and only those with a poor-prognostic cancer. Research into the experience of living with and beyond cancer from five years after diagnosis is sparse. The reasons for this are not clearly stated. As mentioned in chapter eight, many types of cancer are considered to be 'all clear' after five years if there has been no recurrence or progression and people are usually discharged from specialist cancer 'follow-up' at this stage (Drew 2003). Speculatively, and as much cancer-related research seems to arise from cancer care environments, this may suggest that potential research participants become less easily accessible to researchers from these environments at this point as they are not regular visitors to a single healthcare setting. Recruitment is therefore less easy to guarantee in a particular timeframe which may also affect cost and funding. Another possible reason is that, until recently, this population was relatively small and the potential problems associated with long term survival were simply not recognised (Richards et al 2011). However, it is now accepted that a rapidly growing population is surviving well beyond their diagnosis and these people may have ongoing healthcare and emotional needs for many years (Khan et al 2011[c], Maher and McConnell 2011). More research into the consequences of longer term survival for individuals has been called for in the UK (Maher and McConnell 2011, Richards et al 2011, Richardson et al 2011) and internationally (Rowland et al 2006) but the *recovery* of health and well-being is often the focus (e.g. Foster and Fenlon 2011). My study suggests that a full 'recovery', if defined as 'regaining possession' (Oxford English Dictionary 2012), may never be possible and cancer continues to threaten biographical trajectory and self-identity ad infinitum, as eloquently explained by one participant:

[cancer] is portrayed more as an acute illness and actually I think it is more like a chronic illness which you live with. If you ask somebody on the street to describe somebody with cancer, bald head, being sick, the stereotype chemotherapy patient and it is just not like that. You have bits like that but that is not what cancer is. Cancer is like living with an ingrown toenail or something. Do you know what I mean? It is something that is there all the time (30.1).

The research that does exist on longer-term survival has tended to focus on people with 'good-prognostic' cancers, such as cancers diagnosed in childhood or breast and prostate cancers (e.g. Drew 2003, Khan et al 2011[B]). This is understandable as a greater proportion of these groups are likely to survive and for longer. My study is the first to have specifically focused on the many people who are still diagnosed with a cancer with an expected poor prognosis. This is important because their diagnoses are likely to have been perceived as more capricious, their expectations of survival realistically lower and the fear associated with this more reasonable from the outset, which may have made their experience very different. Interestingly, although my participants had a less than 50% likelihood of surviving five years from their diagnosis, eleven were alive and well at or after five years. This number was higher than I had expected. Although this may be partly explained by my recruitment method and the representativeness of my sample (as discussed in chapter seven), it also indicates the individuality of cancer survival which may sometimes be hidden behind statistics.

I also asked, "What are the main concerns and challenges faced by people living with and beyond a poor prognostic cancer?" Even when my participants were effectively 'healthy' and were seemingly established in their 'new normal', a major concern was an unremitting fear of recurrence which acted as a persistent reminder, making 'survivorship' an

ambiguous state. Cancer is unpredictable and there is always a chance, however small, that it will return even after a long remission (Drew 2003, McKenzie and Crouch 2004, Cancer Research UK 2011[D]). For most people diagnosed with cancer, and particularly for those diagnosed with a cancer with a poor prognosis, life expectancy and health status remain in question and 'at risk' forever (McKenzie and Crouch 2004). As such, the study participants were archetypal members of Frank's 'remission society', which he describes as the liminal space inhabited by people living with chronic illness and disabilities who are effectively well but not cured and for whom "the foreground and background of sickness and health constantly shade into each other" (Frank 1995, p9). As Mathieson and Stam explain, "The social space one inhabits is now one of illness, rather than health" (Mathieson and Stam 1995, p300) and the disrupting influence of this appeared to hold strong throughout the sample, even for those who had lived for many years following a cancer diagnosis or been treated for more than one cancer. As one woman, now receiving palliative care for metastatic breast cancer, explained of her resulting lack of independence:

> Long gone are the days where I used to spend all day in a shopping mall with my
> Mum and my sisters because I just can't keep up with them and they did suggest to
> me the shopping malls have the mobility help, don't they? They did suggest I do
> that but I am not doing that. I am not doing that, you know. I will crawl on all fours
> before I do that. I know what they meant but it is giving up that independence that
> you just don't want to do, that is hard (30.1).

I also queried whether the experience of living with and beyond a cancer diagnosis corresponded to any existing theoretical models. Despite the context of our research and our participant groups being very different, my participants described elements of biographical disruption very similar to those described by Bury in 1982 in his study of people with RA (discussed in chapter two). For example, Bury (1982) identifies the need to

try and maintain 'normal' activities and previously held relationships as a key feature of biographical disruption but 'normality' was altered for his participants because activities had to be restricted or carefully co-ordinated in the face of limited ability. In the same way, my participants reported having to manage their lives carefully to incorporate fatigue and post-surgical physical changes. 'Returning to normal' was very important but a changed normality had to be accepted and, like Bury's respondents, this was made stark when participants returned to roles they had held before their diagnosis, such as their employment. Despite legislation that has been passed since and should have prevented the discrimination suffered by Bury's participants, such as the Disability Discrimination Act of 2005 which makes it a legal responsibility for UK employers to make 'reasonable adjustments' to encourage continued employment for people with progressive conditions such as cancer (Amir et al 2010), many of my participants had found the transition difficult or impossible. A large proportion had to retire or work fewer hours and those who did manage to maintain their previously held jobs often felt limited in their ability to change aspects or isolated because fatigue or other problems prevented them taking part in extra-curricular but expected parts of the job, such as social activities or additional working.

Although very limited in number, there are some recent studies which have explored the biographically disruptive elements of responding to or living with a cancer diagnosis. Similar to Bury's study, these have only focused on the initial diagnosis and treatment phase and have therefore just encompassed the more 'acute' phase of a potentially chronic cancer illness. For example, Cayless et al (2009) and Hubbard et al (2010) have researched the first year after a diagnosis of prostate and colorectal cancer respectively and have identified threats to identity, such as adjusting to a changed body image brought about by treatment side effects and an awareness of mortality, which disrupted biographies in both populations. Like my participants, those with newly diagnosed colorectal cancer

interviewed by Hubbard et al (2010) found their identity threatened and future disrupted by a loss of paid work and independence and sought to retain normality by maintaining usual daily activities as much as possible.

My study is one of very few that has explored living *beyond* a year after a cancer diagnosis and has exposed the persistence of biographical disruption. As discussed in chapter two, I have identified three other studies, again focusing on participants with better prognoses, which also confirm the non-resolution of such disruption after a cancer diagnosis. Grinyer (2007) studied British teenagers and young adults between one and five years after a cancer diagnosis and Drew (2003) explored the personal accounts of young Australians at least five years after a diagnosis of cancer in childhood or adolescence. Both found significant biographical disruption, in particular related to body image, sexuality and fertility, postponed or abandoned plans for the future and a loss of physical and financial independence. A recently published study by Hubbard and Forbat (2011) investigated written accounts of Scottish people who had been diagnosed with different cancers (the greatest proportion being breast cancer) for at least a year. As in my research, they found cancer to be a significant and ongoing physical, psychological and social disruption for their respondents, threatening an anticipated life expectancy, course and identity. They also examined characteristics such as age, time since diagnoses and whether respondents considered themselves to be 'free' of cancer or not and concluded that some impacts of cancer were constructed as having a permanent and profound impact on anticipated life and identity, whereas other disruptions were downplayed or presented as effectively managed.

Bury (1982) also explains how individuals need to mobilise resources in order to adapt to their chronically ill status. This is usually described in terms of loss (Charmaz 1983).

However and interestingly, my participants often formulated changes to their selves in positive ways, incorporating 'benefit finding' (Thambyrajah et al 2010) or 'post-traumatic growth' (Scrignaro et al 2011). For example, many reported reducing their social circle to include only the people who really mattered or diverting their energy to new but more enjoyable enterprises. Although benefit finding after cancer has been noted in quantitative research (e.g. Document et al 2012), formal work on the subjective experience of a greater appreciation of life after a cancer diagnoses is, so far, very limited and appears to have been examined only in this study, Hubbard and Forbat's (2011) analysis of people's written accounts and Thambyrajah et al's (2010) work with people with HNC.

Cultural construction, societal perception and representation of cancer

Arguably, the continued disruption and sustained liminality experienced by my study participants was worsened by the cultural construction and representation of cancer within Western society, which gives it a unique and stigmatised status (Sontag 1991, Stacey 1997). Stigma is a characteristic of other illnesses, for example mental illness and HIV/AIDS (Goffman 1963, Weiss et al 2006), and is likely to impact differently but significantly on them too. For example, Bury (1982) describes how some of his respondents restricted their social environments to familiar territory to avoid stigma. However, as Tritter and Calnan (2002) point out, cancer differs from many chronic illnesses because of its prominent media profile, the stigma attached to it and its cultural perception as a highly fatal illness. They suggest that this may enhance any social isolation experienced by people living with cancer. This has been explored by other authors (Butts Stahly 1988, Sontag 1991, Stacey 1997, Seale 2001[A], Seale 2002, Chapple et al 2004, Else-Quest et al 2009) and there are many examples throughout my participants' photographs and narratives of enacted and felt stigma, whereby people felt isolated by the actions of others in response to perceptions about cancer or isolated themselves by behaving in a way they believed was appropriate

for a person with cancer, such as choosing not to 'burden' certain people with information about their diagnosis and treatment (Nettleton 1995, Chapple et al 2004). One participant in her thirties described her problems with communicating her diagnosis and its consequences to her friends:

> Even amongst your friends when you're faced with that, that one of you has got this thing and it's that horrible word, they'll struggle and they'll stutter. They can't say it. People do struggle to deal with it and they don't want to talk about it (4.1)

As McKenzie and Crouch (2004, p141) suggest, being 'on the margins of everyday life' in this way acts to increase liminality and biographical disruption for people with cancer.

Furthermore, Sontag (1991) highlights the dramatic, militaristic words, such as 'fight' and 'crusade', which are used to describe the actions against cancer and claims that by describing cancer as "no mere disease but a demonic enemy" (Sontag 1991, p59), it is made into something shameful for which the person with it becomes culpable. There are examples within the photographs and interviews of my participants of such metaphors and the responsibilities and obligations that ensue, for example when trying to query and rationalise their diagnosis to themselves or others. As one woman described her brother saying when hearing of her diagnosis, "But you never do anything wrong and you've really always tried to do the right thing" (29.2). Stacey (1997), who also wrote about her own experience of cancer and the way it is perceived and made sense of in contemporary society, maintains that cancer is constructed as a physical manifestation of many problems in society (e.g. pollution, crime). She claims that in contemporary Western culture conflict between good and evil remain at the heart of the cancer narrative. She says:

> The person with cancer is offered the opportunity to achieve heroism through bravery, fortitude and strength of will-power. Having faced death and survived, the

hero of this narrative is good and wise and true to themself ... it is impossible to have cancer and not be seduced by the power of such cultural narratives.

Stacey 1997, p13.

Participant-produced photographs have added to the richness of the data produced

My final question asked, "Is photo-interviewing an appropriate and useful method for gathering data about living with and beyond cancer?". Photo-interviewing methods have been used successfully in previous studies to reveal the meaning of cancer diagnosis and treatment (Frith & Harcourt 2007, Oliffe & Bottorff 2007) or cancer survival (López 2005, Poudrier & Maclean 2009, Yi & Zebrack 2010) but such research is so far limited to people with a small number of 'good prognostic' cancer sites (breast, prostate and childhood cancers). Mine is the first to have explored the experiences of individuals with different and poor prognostic diagnoses.

The results of my study confirm that photo-interviewing is an appropriate and useful method for gathering data about living with and beyond cancer for this group of participants. Each was able to produce a number of good quality photographs that they were willing to share and talk about. The general consensus was that it was an enjoyable and worthwhile process for individuals. Although, as described in chapter eight, participants may have been influenced by the conventions of personal photograph composition and sharing, I claim that participant-produced photographs appreciably enriched their data and added to a symbolic interactionist understanding of the experience of living with and beyond a poor prognostic cancer that would not have been available through interviewing alone. I recognise that my claim requires caution because second interviews arguably produce more focused data as participants and researchers have had an opportunity to become acquainted and develop a rapport (Polkinghorne 2005) and I

may have produced more in-depth data simply because I met my participants twice. I am also aware of the 'deceptions' that images can produce, encouraging researchers to believe they 'know' the photographer, rather than simply the image he or she has produced (Piper and Frankham 2007). However, and as Harrison (2002[B]) has noted, the photographs appeared to have both a material and symbolic significance that allowed participants to communicate and narrate their experience in a way that permitted me to understand more fully what those experiences meant. As I described in chapter four, reasons presented to support photovoice and other photo-interviewing methods are that researchers may gain information that they are unable to access by other means, participants may have more control in the research process and visual representations may give a better understanding. These are discussed again but this time drawing specifically on observations and examples from this study:

Researchers may gain information that they are unable to access by other means

According to Springgay et al (2005), creating photographs for research is an embodied and active process that goes beyond representation. Asking participants to take and share photographs with me and contextualise them with an interview allowed me to meet their families and friends, join their social lives, see their homes and gardens and visit their workplaces in a way that I do not think would have been possible by interviewing alone but is extremely important from a symbolic interactionist perspective (Benzies and Allen 2001). In a way it also allowed me to 'see' them interact with family, friends and colleagues and have a greater sense of their identity. Interestingly, and related to the embodied method described by Springgay et al (2005), two participants chose to take me on a 'walk' with them around their local surroundings via their photographs, pointing out things and places associated with their cancer experience.

Participants may have more control in the research process

Asking participants to illustrate their experience through photography appeared to give them more control about the aspects of their experience they shared or emphasised with me and the degree of exposure they chose to give themselves. For instance, some participants placed themselves prominently within the 'picture frame', some took photos of significant people or places but omitted themselves and others took very abstract photographs. Giving participants a few weeks to take photographs also gave them time to fully explore their experience. For example, many talked about incidents that had occurred during the time they were creating photographs which reminded them about an aspect of living with and beyond cancer and prompted them to take a photograph to illustrate it; this is far less likely to have occurred during a single interview (Polkinghorne 2005). Furthermore, it allowed time for people who were less well to fully engage, such as one participant with lung cancer who had a chest infection when I first visited him. This made an interview difficult because of his associated cough and shortness of breath but, during the fortnight he was taking photographs, he fully recovered from his infection and was able to take many photographs outdoors which he used to illustrate his experience in very positive ways. Sharing photographs also allowed participants to talk about people or phenomena that were too difficult to put into words. One woman shared a photo of her father because he had been the most supportive and helpful person to her since her diagnosis but, as he had recently died, she was emotionally unable to speak about him.

Visual representations may give a better understanding

If not a better understanding, photographs in combination with interviews certainly gave a broader understanding of participants' experiences. This is shown by the slight incongruence in codes depicted by photographs and interviews as described in chapter seven, indicating that some issues may have not been highlighted without visual data.

Furthermore, visual representations can combine a metaphorical and sensory dimension (Springgay et al 2005, Rose 2007) and sharing photographs often added an emotional aspect to explanations that may have been less obvious if I had simply interviewed participants. For example, when one woman showed me a photograph of herself completing a run, I was able to *see* the pride in her achievement as well as *hear* about it. In a similar way, participant sixteen became increasingly angry as she looked at a photograph of all the additional things she now has to carry in her handbag to deal with post-surgical side-effects on a daily basis (figure 25). When speaking to her, she tended to present herself as a very positive and cheerful person, so I may have been unable to appreciate how difficult this was for her if I had only spoken to her. Similarly, insights were revealed in the feasibility study when both participants became upset when viewing self-portraits with me (figure 2).

As a nurse, participants' photographs often gave me a stark and personal perspective of something I thought I was fully aware of. For instance, although I am aware that fatigue is a very significant and often unexpected side-effect of treatment (Curt 2001) and I have always endeavoured to warn patients about it, seeing a photograph of a battery (figure 12) and hearing participant six describe feeling as drained as a spent battery by the end of the day has given me a much more vivid appreciation and understanding of its impact. Similarly, seeing participant nineteen's family and friends leaving or turned away (figure 35) has given me a much greater comprehension of the isolation and loneliness that cancer can cause than words alone could have expressed. Other health professionals have also commented on this during presentations of the study results so far. As, Harrison (2002[B]) explains, narratives that involve memory require elements of imagining, picturing and visualising and such sensory information may be misplaced when it is transformed into and filtered through language.

Images presented with associated interview narrative offer a powerful means of communication

Both within this thesis and at various presentations of this work so far, I have chosen to present participants' photographs with their related interview fragments directly alongside them, as well as using interview extracts to illuminate themes within the text. This is rare in photo-interviewing studies; for example, in the cancer-related studies mentioned earlier in this chapter (page 300), only Yi and Zebrack (2010) portrayed their young cancer survivor's photographs and interview extracts together in this way within their published article. However, my reasons for doing this are threefold. Firstly, I consider the photographs require an immediate and unguarded context. As Becker (2003) describes in her work on photojournalism, photographs require words to "surround and penetrate them" (Becker 2003, p302). For example, a picture of a Mercedes sports car means little until it is contextualised by the description of the ambiguous love/hate relationship its owner has with it (figure 20). Secondly, representation with the photographer's own words supports the participatory and empowering philosophy of photovoice, which rejects photographs considered outside of participants' own stories and voices (Wang et al 1998) and reduces the risk of a misguided interpretation of what the photograph *should* be saying (Collier 2001, Sontag 2003, Piper and Frankham 2007). Thirdly, the photographs produced by my participants were produced, not as artistic works for display (although all participants have retrospectively given their consent for them to be used in this way), but as part of a research study employing a symbolic interaction perspective to draw from images *and* interviews to comprehensively explore their experience. However, my preference of displaying photographs with text has raised questions about representation, the politics of exhibiting and debates within semiology (Hall 1997, Lidchi 1997, van Leeuwen 2001, Mitchell 2012).

Although these questions have been addressed to some extent in chapter four, it is not my intention within this thesis to deliberate on them in detail as to do so would be to divert the focus from the research aim of exploring the experience of living with and beyond cancer and move beyond the method of photo interviewing. Nevertheless, it is important to recognise that there are arguments *against* displaying photographs made as part of a research study with associated and explanatory text. For example, it is claimed that captions may simply be used to provide evidence to support a researcher's point of view or that the photographs contain a narrative of their own and might lose some of their emotion if they are 'explained' (Rose 2007, Lysaght et al 2009). However, in accordance with Lysaght et al (2009), I maintain that, when interpreted together, photographs and interviews appear to become greater than their constituent parts and contextualising photographs with associated narratives gives them a power and poignancy of their own. Equally, and as Radley (2002, 2009) argues, images portraying illness alone may cause pity or horror and thus be turned away from, whereas, photographs and text together are able to both describe *and* make visible and therefore allow people who are unwell to create and communicate a role and sense of coherence for themselves. I would also go so far as to agree with Collier (2001) who suggests that contextualising photographs is a moral responsibility in visual research and without annotation they become analytically unintelligible.

There is a long history of presenting images and texts together, from symbols left by ancient cultures and civilisations to books and museum exhibitions from the more recent past (Lidchi 1997, Lysaght et al 2009, Mitchell 2012), According to Lysaght et al (2009) this history demonstrates the power that both sources of narrative have when combined in providing comprehensive information and detailed understanding of the experiences and lives of other people and they suggest that it is when exhibited that the complementary

aspects of text and images read together become particularly important. I have so far presented data in this way to audiences consisting of healthcare staff, academics and related university staff, user and patient groups and charitable and voluntary cancer organisations and it has certainly been my experience that these photographs contextualised with interview extracts create a powerful and significant exhibit and way of communicating and disseminating experience which generates much commentary and debate amongst both professional and lay audiences. As Harrison explains, photographs provide references but go beyond what they represent and, as she states, "It is under or beyond the photograph that the person's story lies buried" (Harrison 2002[A], p104).

Was symbolic interactionism a useful approach for this research?

As described in chapter one, I approached this study using a symbolic interactionist model (Silverman 2000) thus perceiving my participants as active, creative, responsive and reflective members of society and focussing on the subjective aspects of their lives (Mead 1934, Blumer 1969, Tsourvakas 1997). Three basic assumptions underpin symbolic interactionism, which are:

- People do not respond directly and inconsiderately to an event or experience but attach meaning to phenomena and act according to that meaning

- Meaning arises in the process of interaction with other individuals and the way in which those other individuals act to define things and events

- Meaning is specified and modified through an interpretive process which is in constant flux and subject to redefinition, relocation and realignment.

(Blumer 1969, Benzies and Allen 2001).

Symbolic interactionists assume that individuals have freedom of choice, although that choice is constrained by societal and cultural norms, and are able to think in an abstract and reflexive way which enables the development of symbolic language and gesture for communicating meaning and creating common responses from others (Mead 1934, Benzies and Allen 2001). This was clearly demonstrated in my study, for example in the way that participants communicated with others (or withheld information) as described in the key theme 'the involvement of friends and family', the expectations and assumptions that were placed on them and they placed on themselves as described in the key theme 'why me?' and their ambivalence to the embodied and environmental visibility of their previous diagnosis and changed identity as described in the key theme 'a "new normal"'.

Benzies and Allen (2001) argue that the most important principle of symbolic interactionism is the idea that the individual and the context in which he or she lives are inseparable. An example of this would be the way in which people with cancer may be defined by their diagnosis as experienced by both Stacey (1997), Ehrenreich (2001) and participants in the study (e.g. 26.1).

Symbolic interactionism has been criticised for not giving adequate attention to social institutions and issues of economic and political power or to unconscious and emotional factors that may influence behaviour (Bilton et al 1987, Benzies and Allen 2001). Certainly, the claim that society consists only of the perceptions and definitions of individuals is unsustainable and the consequences of factors such as class, gender and – in this case – the side effects of disease or treatment are real and need to be recognised. However, symbolic interactionism has proved to be an extremely valuable and practical approach to exploring the lives, perceptions and understanding of others and learning how they make sense of

the world and cope with unfamiliar events or influences, such as managing the changes

produced by a cancer diagnosis (Bilton et al 1987, Benzies and Allen 2001).

Conclusion

In this chapter, I have discussed the key findings and sociological implications of this study.

In chapter ten, I will reflect on some of the important considerations that arose from the

execution of the study, including a consideration of the process of the 'photovoice' method

I used by participants and a description of a conflict I personally experienced between my

professional nursing and qualitative researcher role. I also consider some possible

directions for future research and implications for health care staff that have arisen from

the research process and results.

Chapter 10

Participant and researcher reflections on the study

Introduction

The importance of self-scrutiny and reflection has been stressed within both traditional qualitative (Mason 1996, Rolfe 2006) and visual methodologies (Rose 2007, Mitchell 2011). Without reflexivity, defined as an awareness of the multiple influences that researchers have on the research process and how the research process might affect them (Gilgun 2010), it has been argued that research cannot claim to be either plausible or believable (Koch and Harrington 1998). In this chapter I reflect on some of the important aspects that arose from the methods and outcome of my study. I start with a discussion about participants' considerations of the process of creating their own photographs and communicating their experience via this medium. I then describe the conflict I encountered between my professional 'helping' role of a nurse and my 'listening' qualitative researcher role. Finally I consider some possible directions for future research and implications for health care staff that have arisen from the research process and results.

Taking photographs for a research study: reflecting on the process with participants

After the two interviews, I asked all participants the question, "How did you find the process of taking photographs to illustrate and demonstrate your experience?" The responses I received may well have been biased because I was the researcher and it was me asking the question (Bowling 1997) but, because of the novelty of the method, I thought it was important to try and understand whether the process had been useful or difficult for participants. I was also aware that the experience might have been cathartic for

some but was concerned that it may have been distressing for some people and wished to investigate this.

Two participants said it had been "a bit crazy really" (16.2) and "it was strange doing it" (2.2) but, encouragingly, nobody found it unhelpful and twenty five said they had positively enjoyed it, for example saying, "it was fun" (16.2). Furthermore, two participants and the partner of one e-mailed me afterwards to say how helpful and enjoyable the process had been for them. One described it as "a challenge" (23.2) and another as "quite tricky" (26.2) but most said it had not been difficult for them to either think of subjects or take the photographs once they had started.

There has been no work into the therapeutic value of using photography after a cancer diagnosis or treatment and I am keen to stress that this was *not* an aim of this study. However, some participants did describe positive effects of taking or viewing their photographs, for example:

> I think it's made me sort of think what my life's about and there's nothing in these photos about possessions because they don't mean anything to me, you know. They really don't mean anything to me ... it's all about my time I think; time and giving people time (17.2).

> It's like I've been able to take a picture like a bad picture and put a bit of anger into that. I've snapped that shutter on the camera and ... it's told me this is what you look like on the sofa, you look a mess, pull your finger out. From a girl who never used to go out of the house without mascara on. So I think it's been helpful in that way and I think it's definitely made me open my eyes a little bit and appreciate things (20.2).

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I'm a lot more positive than I thought when I look at the ones I chose. So in a way it's made me think, I do get fed up and down and what have you [but] the time has gone on and I've got better (9.2).

So far, the literature on participant-produced photography has focused on it as a research method and although its therapeutic value is reported in theory, it is merely anecdotal (e.g. Yi and Zebrack 2010). However, evidence that supports other artistic and creative approaches as therapy has recently been growing and Wood (2005), drawing from her own literature review on art therapy, lists the following potentially positive outcomes:

- Better communication

- Development of a creative attitude by patients towards their circumstances

- An increased sense of control

- An addressing of body image concerns

- Increased self esteem

- Increased quality of life

- An increased ability to confront existential questions and relieve spiritual distress

- Development of positive coping strategies

- A reduction in experiences of physical pain.

Furthermore, drawing from psychoanalytic theory, it has been argued that qualitative research interviewing provides an interaction that is therapeutic for people with cancer and other illnesses (Colbourne and Sque 2005, Dickson-Swift et al 2006).

Oliffe and Bottorf (2007) reflect on the method of photo-interviewing that they used while doing research with Canadian men living with prostate cancer. They describe the process as

being both physically and cognitively active and involving constructing and reconstructing rather than simply retelling a verbal story, which allowed their participants to consider carefully what they wanted to discuss. They say their participants enjoyed creating as well as viewing and explaining their photographs. They also suggest that the use of photographs helped to break down the potential gender-constructed stoicism related to interviewing men about health and illness and facilitated the associated interviews. My sample was biased towards women and I was unable to detect any particular gender difference in participants' narratives. However, all the interviews provided rich data and participants did not appear to have any difficulty describing their experiences. Photographs may have assisted this and certainly seemed to allow participants to emphasise certain situations and hone experiences.

The intention of my study was to explore experience and I would never claim that participants benefitted from taking part. However, it was interesting to receive such positive feedback from many of them, which perhaps should not be ignored. I maintain that there should be a wider debate about the therapeutic value of involving people living with and beyond cancer in creating and sharing photographs to explore their experience and would like to direct future work towards this phenomenon (described more fully later in this chapter).

A nurse and researcher: Reflecting on crossing professional boundaries

Qualitative methodologies assume that both researchers and participants are active contributors to the research process and research outcomes are the result of collaboration between them (Dickson-Swift et al 2007, Underwood et al 2010). Furthermore, one of the basic assumptions of symbolic interactionism is that meaning arises from interaction with

others (Mead 1934, Blumer 1969, Benzies and Allan 2001). As such, the identity of the researcher is as important as that of the participants because the researcher is actively involved in the social construction of the research reality and their values, beliefs and experiences will influence the questions asked and interpretation of results (Horsburgh 2003, Hewitt 2007). Factors recognised as influencing the relationship between researchers and participants include age, gender, appearance, social class, culture and inequalities of knowledge and power and it is suggested that social distance can result in lack of trust and suspicion (Miller and Glassner 1997, Hewitt 2007). Building rapport and having empathy are therefore seen as key in reducing any such distance and boundaries as much as possible and ensuring trust is established and confidentiality is assured (Miller and Glassner 1997, Rowling 1999, Rager 2005, Dickson-Swift et al 2007, Jack 2008, Gair 2012). As Benzies and Allan (2001) stress, research conducted within a symbolic interaction framework is participant-centred and researchers have a responsibility to be sensitive to the lives and circumstances of those they wish to study and the potential impact of the research involvement on participants. As an experienced cancer nurse, I believe myself to be a confident and sensitive communicator with people who are at all stages of a 'cancer journey'. However, and unexpectedly, this professional background also created some difficulty for me. Although reported anecdotally, nursing and allied health professional literature tends to focus on technical skills in research and there has been little work published that addresses this issue of professional role conflict specifically (Rowling 1999, Jack 2008) but I became aware that, as a nurse, I was accustomed to 'doing' things for people with cancer; such as acting as their advocate or helping to alleviate the problems they expressed. It was difficult to reconcile the need to build a rapport with the need for a degree of research objectivity *and* to prevent myself from 'protecting' participants. Although recommendations on the most appropriate amount of reciprocity and researcher self-disclosure is mixed (Dickson-Swift 2007, Jack 2008), I aimed for what Rowling (1999,

p171) calls 'empathic distance' or being aware and responsive to social obligations but also realising that I was not part of each participant's social world and therefore refraining from drawing from my own personal experience as much as possible. I consequently tried to avoid being 'a nurse' and offering advice so that my influence on the participants' narratives was reduced but when people were visibly upset or anxious, it was difficult *not* re-assure when I felt I would be able to and sometimes I did at the end of the interview if it was appropriate.

Richards and Emslie (2000) discuss the interview interactions they encountered when interviewing Scottish men and women about heart disease. Despite being the same gender and of similar age and social backgrounds, Richards, a general practitioner who chose to reveal her professional background to participants for ethical and methodological reasons, found that she received much more deference from working class participants and much more medical and hospital related information from all participants. Whereas, Emslie, a sociologist, who introduced herself simply as a 'researcher', was aware that she experienced a more personal interaction and often received information that criticised healthcare professionals or care. They suggest that professional backgrounds should be considered carefully when planning, performing and disseminating research. Similarly, and in line with ethical guidelines, I introduced myself as a nurse on meeting my participants, which may have influenced their perception of me and perhaps made them more expectant of help and advice from me (Colbourne and Sque 2004, Jack 2008). Co-incidentally, many did ask for specific health-related information, for example about managing emotional responses, possible causes of cancer and dietary advice. Although, I helped where I could, I tried to keep this separate from the interviews by, for example, sending an e-mail later. I am also aware that the participants' perceptions of my

professional identity may have influenced what they chose to tell me and the photographs they decided to share with me (Dickson Swift et al 2007, Jack 2008).

Dickson-Swift et al (2007) interviewed qualitative health researchers about the practical challenges they had encountered when conducting research into sensitive topics, including the experience of cancer. They used the term 'privilege' to describe their experience of being privy to their participants' stories, especially when it may have been the first time that a particular story had been told. I too felt hugely privileged that participants were prepared to share so much and be so candid with me. However, Dickson-Swift et al (2007) also reported that some of their respondents felt 'desensitised' after hearing many difficult stories and felt they had become immune to more distress. I did not relate to this at all; instead I found sitting and quietly listening to people's cancer stories and viewing their photos with them was an emotional and humbling experience and remained special and unique throughout the data collection period. As an experienced nurse, I thought interviewing people with cancer would be unproblematic but I now appreciate that in the clinical arena, the focus on 'making things better' sometimes detracts from spending an extended time with one person, actively listening and being attentive to the minutiae of what they are saying.

Future directions for research

The process and results of my principal study have highlighted several areas of limited sociological and health-related knowledge in which research could be continued or directed. These are outlined below.

Influences on biographical disruption

This study emphasised the biographically disruptive elements of living beyond a cancer diagnosis. Several factors have been highlighted in the literature as possibly influencing the impact of biographical disruption. It would be interesting to investigate these further and their applicability to specific 'groups' of people in order to increase understanding about living with and beyond cancer. For example:

- Fatigue

Fatigue was an important consideration for my participants, even many years after their cancer treatment, and impacted on important areas of their lives such as returning to paid work, engaging fully in their role at work and maintaining a social life (e.g. figure twelve; fatigue). Fatigue has also been highlighted as problematic in other populations after cancer treatment (Spelten et al 2003, Lawrence et al 2004, Reeve et al 2010). There are certain measures of fatigue available, although none have so far managed to incorporate fully the multi-dimensional and specific aspects of cancer fatigue (Pascal et al 2007). It would be useful to locate or produce an appropriate measure of physical and emotional fatigue in order to investigate its influence on biographical disruption with a view to predicting who is more likely to be affected and therefore to manage proactively.

- Age

Age has been noted to be a factor in both people with cancer and other chronic illnesses, with younger people seemingly experiencing greater disruption and older people almost expecting the inevitability of ill health. However the age ranges in these studies have tended to be discrete and there has been little comparative work. My study recruited a small group of people with mixed ages. It would be interesting to research a bigger group

and determine whether age itself or the social circumstance related to age (e.g. retirement, co-morbidities, living alone) have a greater or lesser influence on biographical disruption.

- Cancer diagnosis

Some cancer diagnoses are associated with greater felt and/or enacted stigma, such as lung cancer and others that are perceived to be caused by the individual's behaviour (Chapple et al 2004, Else-Quest et al 2009, Gonzalez and Jacobsen 2010). Some of the participants in my study alluded to this and a more in-depth exploration of the influence of health promotion, shame and blame and how these may or may not feed into lay perceptions of cancer causation and affect the degree of disruption experienced would be worthwhile to increase understanding, particularly around issues such as late presentation (Tod et al 2008) or impediments to seeking support (Chapple et al 2004).

New understanding about living with cancer and its effects on identity

My participants described two previously unexplored factors associated with the impact of a cancer diagnosis on personal identity. Firstly, those less obvious or usually hidden changes in appearance also created an ongoing legacy for many (see figure 16 'people won't know'). Although issues related to 'unseen' body image changes are discussed in the literature, for example Juraskova et al's (2003) study of adjustment after cervical and endometrial cancer, they have tended to concentrate on sexual function and fertility issues, whereas, for my participants, such changes caused by cancer or treatment or less directly related factors, such as looking or feeling older or being unable to maintain weight appeared to have a significant impact on identity, irrespective of age, gender or whether participants were partnered.

Secondly, participants reported that their identity was also affected by changes in the home and/or social environment (for example, figure 13; menu and figure 17; my bedroom). There has been a limited amount of work related to this in rehabilitation and disability research, such as Gitlin et al's (1998) investigation into the acceptance of assistance devices by older people who have experienced a stroke. However, the social and cultural implications of alterations in people's homes or social spaces are new phenomena in cancer research. As more people survive cancer and for longer, both these factors may be represent growing problems and it would be helpful to explore them further to understand the impact of cancer and cancer rehabilitation on personal identity more fully.

Fear of recurrence

Participants expressed an extreme and unremitting fear of recurrence often preventing them from investing financially or emotionally in the future even many years after they were discharged from specialised oncological follow-up. This fear has been described in other studies of people living after cancer diagnoses, however there has been criticism that the majority of studies investigating this have focused on women with breast cancer (Richardson et al 2011). It is not possible to establish from this study whether the fear described by my participants was greater because of their diagnosis of a poor prognostic cancer and the news of a recurrence being more likely. I am now involved in a plan to investigate this further with colleagues from Warwick University with a view to exploring the phenomenon of fear of recurrence in samples of people with different types of cancer and considering the efficacy of a psychological intervention to help people manage this more effectively. There has been a recent call for investment in such research (Richardson et al 2011).

Effect on carers, family members and friends

Undoubtedly, a diagnosis of cancer has a considerable impact on the carers, family members and friends of the person with cancer as well as the directly affected individual (Thomas and Morris 2002, Pitceathley and Maguire 2003). For instance, Young et al (2002) have investigated the experiences of mothers of children with cancer and detected that they undergo archetypal biographical disruption and Harrow et al (2008) have identified similar effects on identity and social interaction in male partners of women with breast cancer.

Many of my participants expressed difficulty in communicating with family and friends, which caused them to feel isolated and, in two cases, almost led to divorce. This supports limited work formally produced suggesting that people with cancer may practice 'emotional caring' of others to the detriment of their own wellbeing (McKenzie and Crouch 2004). I propose that it is necessary to use a symbolic interactionist model (Silverman 2000) to explore in depth how people with cancer and their family members, friends and colleagues talk about and identify with cancer and its personal impact and/or create distance between it and them and investigate whether this is influenced by, for example, societal and cultural perceptions of the disease, opinions about the responsibility to care for others and 'felt' and/or 'enacted' stigma, as all these have the potential to impact on the wellbeing of both the person with cancer and those close to them.

Therapeutic value of photo-interviewing techniques

As discussed earlier in this chapter, participants appeared to find some therapeutic value in the process of creating images to illustrate their experience. Although this has been discussed theoretically (e.g. Radley 2009) and there is some work to suggest that art making has a positive value for people with cancer (Waller and Sibbett 2005), I have been

unable to find any specific empirical work on the healing function of creating photographic images. Photography allows a more immediate method of expression and may be an easier and more practical medium than other art-making for many people (Sontag 1979, Falk 2005). Therefore I would be very interested to investigate whether it has a positive and therapeutic effect. Evidence could potentially be gathered via case studies or focus group discussions. It may be possible to extract more objective data via measures of 'wellbeing', for example, the Measure Yourself Concerns and Wellbeing (MYCaW) questionnaire which is a participant focused measure designed to evaluate complementary therapies in cancer support and care (Paterson et al 2007).

Novel ways of presenting data

Presenting photographs with their associated interview text has proven to be a very powerful and evocative way of communicating information about the experience of living with and beyond cancer so far (and is discussed further in chapter nine). I would therefore like to consider the impact of this in a more empirical way and investigate possible new ways to disseminate such data. As mentioned in chapter seven, I am going to present some of the photographs with their associated interview extracts at an exhibition at the NIHR INVOLVE Conference in November. I plan to produce a brief questionnaire and Likert scale in order to assess attitudes towards such visual data display (Bowling 1997) which may be explored in more depth at a later date. Although it would require participants to re-consent to allow use of their spoken narratives, I would also be keen to explore the possibility of broadening such an exhibition to an audio-visual presentation or webcast that displays participant's photographs illustrated with their own verbal descriptions, in order to investigate a more sensory evocation of the research results (Harris and Guillemin 2012) and potentially disseminate the study findings further and reach new audiences.

Implications of the study for health care

The subjective experience of ill health is poorly reflected in the contemporary models of

health and illness that are used to shape medical practices and policies (Little et al 1998).

This has been highlighted as a serious problem by those who have encountered ill-health

and research exploring such matters has been called for (Wright et al 2006, Corner et al

2007). Furthermore, new models of care are required to address the needs of the

increasing number of cancer survivors (Richards et al 2011).

The aim of this study was exploratory and it has investigated aspects of the subjective

experience of living with and beyond the diagnosis of a poor prognostic cancer from a

symbolic interactionist perspective. As such, its strength is in raising awareness rather than

offering solutions. It is hoped that the appropriate dissemination of this work, with the

addition impact of participant-produced photographs, will lead to a greater awareness and

prompt debate among health professionals and policy makers about the way diagnoses of

poor prognostic cancers disrupt lives, threaten identities and jeopardise future plans both

in the short and long term, the huge impact this can have on social, psychological and

sometimes physical functioning and the way in which this can be exacerbated by the

societal perception of cancer and enduring stigma that it engenders.

However, there are some specific areas, highlighted by participants, which make it possible

to suggest some ways in which the results of this study may have direct implications for

health care and policy. These are presented here.

The effect of 'cancergazing'

Participants described how fear of recurrence was often exacerbated before a test or

appointment. Although some cancers benefit from surveillance so that recurrences can be

detected and treatment started early (Kattlove and Winn 2003), for many the optimal

surveillance strategies after treatment are uncertain as most recurrences are detected by

symptoms (Pfister et al 2004, Jordens et al 2010). For example, the recently reported

Medical Research Council OV05 trial investigating the timing of treatment for ovarian

cancer relapse based on serum levels of CA125 (an ovarian cancer tumour marker), found

no evidence of a survival benefit with early treatment on the basis of raised CA125 alone

and the authors therefore rejected routine CA125 surveillance in the post-treatment

follow-up of women who have had ovarian cancer (Rustin et al 2010). Furthermore, women

who were treated early on the basis of a raised CA125 achieved poorer scores on quality of

life measures (Chitale 2009). As such, it is important that health professionals are aware of

the anxiety and fear they may be causing by what Jordens et al (2010) call 'cancergazing'

and it may be pertinent to question the utility of some investigative technologies if they

have limited clinical value and have the potential to 'contaminate' a period of remission by

detecting a recurrence at a subclinical stage (Jordens et al 2010).

The 'tyranny of cheerfulness'

Although some of my participants expressed a greater appreciation of things, people and

events after a cancer diagnosis, there has been concern from some commentators,

including those who have experienced cancer themselves (e.g. Ehrenreich 2001), that this

may be influenced by "the tyranny of cheerfulness" (King 2006, p101) that surrounds

cancer and is linked to the cultural belief that frustration, isolation and misery are causes of

cancer and cheerfulness and optimism will aid recovery. O'Baugh et al (2003) have

compared the perceptions of 'being positive' between people with cancer and their nurses

and concluded that nurses' perceptions have the potential to be very demanding on

patients as they encourage and expect patients to be accepting and hopeful, look on the

bright side, have a 'fighting spirit', take control and participate in support groups. Nurses

saw anger, being withdrawn or doubting the effect of treatment as negative and unhelpful. It is therefore important that nurses and other healthcare staff are aware of the impact their perceptions may have on patients and the extra pressure they may unconsciously create.

The health promotion message

The cancer prevention message is persuasive and often linked to issues of morality and responsibility in which 'victims' are blamed for their own ill health with little acknowledgement of wider determinants of health, such as deprivation (Davison et al 1991, Nettleton 1995, Fitzpatrick 2001, Seale 2001[A]). This feeds into lay knowledge and promotes a complex, stereotypical view of the people most likely to develop cancer and the behaviours that can lead to cancer, as explored in my literature review of lay knowledge and cancer (see chapter three).

Many participants had been bewildered when they were first diagnosed and subsequently because they did not think they fitted this stereotype of the 'type of person' who they believed should have cancer or, at least, their type of cancer. Some felt guilty about their diagnosis; others felt angry because they did not think they 'deserved' it. Furthermore, many participants reported feeling judged and having to defend their diagnosis to others, including their own family, friends and healthcare staff. This is supported by quantitative research and personal accounts in which the causes individuals ascribe to their cancer diagnosis has been shown to affect quality of life, psychological and social adjustment and distress levels (Sontag 1991, Stacey 1997, Ferucci et al 2011).

Few people would argue against disseminating information about cancer risk in a way that allows people to make informed decisions about behaviour that is *known* to significantly impact on cancer causation. However, healthcare professionals must also be aware that overemphasis on individual behaviour may contribute to the creation of a culture of blame in which people with cancer are made to feel culpable for their illness and where consideration of and research into other cancer causes is sidestepped (Fitzpatrick 2001, Chapple et al 2004).

Conclusion

Within this chapter, I have reflected upon some of the issues that have arisen from carrying out this research, for both me and the participants. Photovoice is a very 'new' method. A review of literature published up to 2008 reported that only just over a thousand people had ever taken part in a photovoice study at that point (Catalani and Minkler 2010). Although researchers have largely been very positive about the participatory and empowering nature, I wished to explore this in practice and examine the reality of it for this particular group. Although my method was biased as I (as the researcher) was the one asking participants about their experience, I was reassured by the quantity and quality of positive feedback. I have also discussed the unexpected conflict I felt when attempting to reconcile my primary role as a qualitative researcher working within a symbolic interactionist framework with my usual role in the presence of people with cancer, which is that of a nurse. Finally, I have reflected upon and suggested some potential areas of further research that have been highlighted by both the study process and results and some implications that the study raises for healthcare staff.

My final chapter will present a conclusion to the thesis.

Chapter eleven

Conclusion to thesis

The aim of my thesis has been to investigate the experience of living with and beyond cancer from the perspective of people diagnosed with a 'poor prognostic' cancer and contextualised within the social and cultural representation of cancer in contemporary UK society. The motivation behind this work was my professional awareness of the disparity in increasing cancer survival and concern for what this might mean for people diagnosed with a less 'survivable' cancer, my sociological interest in the cultural representation of cancer, the call from people affected by cancer for research into the impact on life and how to live with cancer (Corner et al 2007) and the NCSI priority for an identification of the psychological and social impact of cancer and how this impacts on the needs of 'survivors', (Richards et al 2011, Richardson et al 2011).

I approached the work from a symbolic interactionist perspective, thus focusing on how social roles are constructed and perceived through interaction and communication and emphasising the social environment's role in behaviour (Blumer 1969, Bowling 1997, Benzies and Allen 2001). To frame my study, I drew upon a theoretical exploration of illness narratives and biographically informed perspectives of chronic illness (e.g. Bury 1982, Charmaz 1983) and a literature review of the lay knowledge of cancer.

Having an epistemological loyalty to participatory research methods and being aware that a cancer diagnosis may make an in-depth interview difficult for some people because of physical or emotional issues, I chose a research method for my empirical study that allowed an alternative method of data collection. As such, I employed an adapted 'photovoice' method which used interviews in combination with participant-produced photographs to

express knowledge and illustrate experience (Wang and Burris 1997, Wang et al 1998, Baker and Wang 2006). Although my feasibility study was not successful in creating a helpful amount of data due to recruitment problems, it did show that participants were able and willing to create their own photographs to illustrate and explain experience. I felt the potential for using participant-produced photographs was worth pursuing and, after increasing my participant inclusion criteria and changing my methods of recruitment, I achieved a successful principal study that drew data from thirty participants.

The six discrete but related key themes identified from the participants' photographs and narratives from the principal study have highlighted aspects of the experience of living with and beyond cancer for this group, which consisted of people of mixed ages and cancer diagnoses who had been living with that diagnosis for between one and seventeen years. Importantly, the participants revealed that living with and beyond cancer was a persistently disruptive experience for them, comparable to the biographical disruption originally described by Bury (1982), and continuing well past the time that they are considered to be 'cured' in biomedical terms. Although a 'return to normality' was prized, a 'new normality' had to be accepted and the fear of a recurrence was a constant reminder which impacted on future plans and participants' perceptions of themselves as 'cancer survivors'. Some participants had enduring symptoms or treatment side effects which added to their disruption but it was often worsened by the societal perception of cancer and stigmatizing opinions about people with cancer. This appeared to bestow certain responsibilities and obligations on the participants, for example impeding communication with colleagues, friends and even family. So far, the research in this area is very limited and centres mainly on people living within their first 'acute' year of a cancer diagnosis. The experiences of people given a poor prognosis have been included within other studies of the subjective experience of cancer but mine is the first to have focused on this group specifically. The

results of this study add to the sparse understanding of the experience of cancer and 'cancer survivorship' for people who have moved beyond the 'acute' treatment and immediate post-treatment.

Furthermore, although photo-interviewing methods have been used successfully in previous studies to explore the meaning of cancer diagnosis and treatment or survival (López 2005, Epstein et al 2006, Frith & Harcourt 2007, Oliffe & Bottorff 2007, Poudrier & Maclean 2009, Yi & Zebrack 2010), my study was the first to use it in a population who were living with the long term symptoms and side effects of a poor-prognostic cancer diagnosis and treatment. It proved to be a straightforward means of data collection for these participants and an effective method which appeared to add to the depth and context of the interviews, reveal more data than would have emerged from interviews alone and produce a broader understanding of relevant issues.

The practice I have adopted of presented participant-produced photographs and related interview text together, although unusual, has offered a powerful and relevant way of exhibiting and communicating experience to various professional and lay groups and has the potential to reach a far greater and more diverse audience.

Finally, I have offered some suggestions for future research and described some implications for health professionals and policy makers that have arisen from the study process and results.

In the UK, the number of people living beyond a cancer diagnosis is growing by 3.2% per year (Maher and McConnell 2011, Glaser 2011). So far there is very little evidence about how best to tackle the short and long-term physical, psychological, social and emotional

effects that are expected to occur, the specific actions that will be necessary to improve health care and delivery or even what some of the longer term effects will be (Richards et al 2011). As more and more people live further beyond a cancer diagnosis these results offer an important insight. It is my intention that key findings of this work will raise awareness of some of the features of living with and beyond cancer and how they affect the lives and identities of the increasing number of people for whom this is a reality. The results will be publicised to professionals and policy makers so that appropriate care and services can be planned and provided. However, through careful and comprehensive dissemination (see appendix 6), I also plan to reach a wider audience so that the issues related to living with and beyond cancer and the impact of perceptions of cancer can be understood and discussed more generally within society.

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Abbreviations (not in general use)

CAQDAS   Computer-Assisted Qualitative Data Analysis Software

CHD   Coronary Heart Disease

CRUK   Cancer Research UK

CRN   Clinical Research Network

HNC   Head and Neck Cancer

NCIN   National Cancer Intelligence Network

NCIS   National Cancer Survivorship Initiative

NCRI   National Cancer Research Institute

NCRN   National Cancer Research Network

NIHR   National Institute of Health Research

NMAHP   Nurses, Midwives and Allied Health Professionals

PHT   Poole Hospital Trust

PPI   Patient and Public Involvement

PHRU   Public Health Research Unit

PRISMA   Preferred Reporting Items for Systematic Reviews and Meta-Analyses

QEH   Queen Elizabeth Hospital

QOL   Quality Of Life

RA   Rheumatoid arthritis

SALT   Speech And language Therapist

SHA   Strategic Health Authority

UHB   University Hospitals Birmingham

UHCW   University Hospitals Coventry and Warwickshire

WHO   World Health Organisation

WMSHA   West Midlands Strategic Health Authority

Appendices

Appendix 1:

Research ethics approval letter: Feasibility study

06 November 2009

Telephone: 024 7696 7529
Fscsimile: 024 7696 5033

Miss Claire Balmer
Clinical Trial Co-ordinator / PhD Student
Warwick Medical School
Warwick Clinical Trials Unit
University of Warwick
Coventry
CV4 7AL

Dear Miss Balmer

Study Title:	**Living with and beyond head and neck cancer: A feasibility study to investigate what it is like to live with and beyond a diagnosis of, and treatment for, head and neck cancer.**
REC reference number:	09/H1210/93
Protocol number:	Version 1

Thank you for your letter of 04 November 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chairman.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is

available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.
*Where the only involvement of the NHS organisation is as a Participant Identification
Centre, management permission for research is not required but the R&D office should be
notified of the study. Guidance should be sought from the R&D office where necessary.*

Sponsors are not required to notify the Committee of approvals from host organisations.

**It is the responsibility of the sponsor to ensure that all the conditions are complied
with before the start of the study or its initiation at a particular site (as applicable).**

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter	C Balmer	11 September 2009
REC application	IRAS	02 September 2009
Protocol	Version 1	13 March 2009
Academic Supervisor CV	Prof J Dunn	08 September 2009
Investigator CV	C Balmer	11 September 2009
Letter of invitation to participant	Version 1	29 July 2009
Participant Information Sheet	Version 1	29 July 2009
Participant Consent Form	Version 1	29 July 2009
Participant Consent Form: Photo Reproduction Permission Form	Version 1	20 July 2009
Evidence of insurance or indemnity	Marsh Insurance Certificates University of Warwick	17 July 2009
Participant Information Sheet	Version 1.1	03 November 2009
Participant Consent Form	Version 1.1	03 November 2009
Response to Request for Further Information	letter C Balmer	04 November 2009

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for
Research Ethics Committees (July 2001) and complies fully with the Standard Operating
Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research
Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National
Research Ethics Service and the application procedure. If you wish to make your views
known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed
guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports

- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our reference group please email referencegroup@nres.npsa.nhs.uk.

09/H1210/93	Please quote this number on all correspondence

Yours sincerely

Mr Stephen Keay
Chairman

Email: pauline.pittaway@uhcw.nhs.uk

Enclosures: "After ethical review – guidance for researchers", SL- AR2

Copy to: Peter Hedges, University of Warwick
R&D office for UHC&W NHS Trust

Appendix 2:

Research ethics approval letters: Principal study

NHS

Coventry & Warwickshire Research Ethics Committee

Prospect House
Fishing Line Road
Enfield
Redditch
B97 6EW

Telephone: 01527 582531
Facsimile:

07 October 2010

Miss Claire Balmer
Research Fellow
Warwick Medical School
Warwick Clinical Trials Unit
University of Warwick
Coventry
CV4 7AL

Dear Miss Balmer

Study Title:	**Living With and Beyond Cancer: A study to investigate what it is like to live with and beyond a 'poor prognostic' cancer in contemporary society.**
REC reference number:	10/H1211/32
Protocol number:	N/A

The Research Ethics Committee reviewed the above application at the meeting held on 29 September 2010. Thank you for attending to discuss the study with Dr Griffiths

Ethical opinion

In discussion with the committee the following points were clarified:

The Committee asked why you have decided to exclude non-English speaking patients?

You said it would be very useful if I could but unfortunately I do not have the funding as this is very limited. It would be very expensive to use translators and the interviews would also need to be translated which would be very costly.

Is this a private study or is it part of your PhD?

This is for part of my PhD.

You have in that case answered question 9 of the filter page incorrectly which will slightly change some questions on the form and also means it is acceptable not to include non-English speaking patients.

What is in place for immediate care for the patients if they become distressed during the interview?

In the immediate situation I would be able to cope as I have visited patients in their homes many times before and have experience with these types of situations.

➤ **The PIS should mention that this is part of an educational study.**

Yes, I will add that to the PIS

➤ **The indemnity you currently have is for negligent harm but with this type of study it is more likely you may need cover for negligent harm so that may be worth looking into.**

I will look into this.

➤ **The consent form does not mention the interviews are to be audio taped this should be included.**

I will add this in.

➤ **There is a typo in the advertisement which reads 'stay' this should read 'say'.**

I will amend this.

As a suggestion it may be worth informing someone of your whereabouts when visiting patients in their homes.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

Other conditions specified by the REC

- The application filter page question 9 will need to be answered correctly and a new copy of the full application form completed signed and submitted to the committee.

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It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Investigator CV		12 June 2009
Protocol	v1	14 June 2010
CV - Key Collaborator		01 May 2010
Letter from Funder		15 September 2009
REC application		06 August 2010
Covering Letter		06 August 2010
Summary/Synopsis		10 August 2010
Letter from Sponsor		10 August 2010
Interview Schedules/Topic Guides	v1	14 June 2010
Advertisement		10 August 2010
Letter of invitation to participant	v1	14 June 2010
Letter of invitation to participant	v1	14 June 2010
Participant Information Sheet: PIS part 1&2	v1	14 June 2010
Participant Consent Form: Consent Photographs	v1	14 June 2010
Participant Consent Form: Consent Form	v1	14 June 2010
Evidence of insurance or indemnity		03 August 2010

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments

- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H1211/32	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Anne McC

Anne McCullough [Mrs] on behalf of
Dr Helen Brittain
Chair

Email: anne.mccullough@westmidlands.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers"

Ms. Ceri Jones
Research & Development Department
UHCW
Clifford Bridge Road
Coventry
CV2 2DX

Copy to: Ms. Ceri Jones
Research & Development Department
UHCW
Clifford Bridge Road
Coventry
CV2 2DX

Coventry & Warwickshire Research Ethics Committee

Attendance at Committee meeting on 29 September 2010

Committee Members:

Name	Profession	Present	Notes
Dr Jane V Appleton	Nurse	Yes	
Mr Roger Balcombe	Retired Chartered Engineer	Yes	
Dr Helen Brittain	Clinical Psychologist Retired	Yes	
Mrs Barbara Canning	Senior University Lecturer	Yes	
Mr Roger Cross	Senior Clinical Pharmacist	Yes	
Mr Matthew Dunn	Consultant Accident and Emergency	Yes	
Mrs Moya Horton	Retired University Lecturer (Physiotherapy)	Yes	
Dr Ashok Roy	Consultant Psychiatrist/Children and Adults lacking Mental Capacity	Yes	

19 November 2010

Miss Claire Balmer
Research Fellow
Warwick Medical School
Warwick Clinical Trials Unit
University of Warwick
Coventry
CV4 7AL

Dear Miss Balmer

Full title of study:	**Living With and Beyond Cancer: A study to investigate what it is like to live with and beyond a 'poor prognostic' cancer in contemporary society.**
REC reference number:	**10/H1211/32**

Thank you for your letter of 8 November 2010. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 07 October 2010. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

Document	Version	Date
Email correspondence confirming indemnity cover		12 October 2010
REC application		03 November 2010
Covering Letter		03 November 2010
Advertisement		12 October 2010
Participant Information Sheet: PIS Part 1 & 2	V 1.1	12 October 2010
Participant Consent Form	V 1.1	12 October 2010

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

10/H1211/32	Please quote this number on all correspondence

Yours sincerely

Anne McCullough (Mrs)
Committee Co-ordinator

E-mail: anne.mccullough@westmidlands.nhs.uk

Copy to: Peter Hedges, University of Warwick

Appendix 3:

Participant information leaflet and consent form: Principal study

Please note that all literature intended for participants was originally produced with version numbers and in a larger font but has been reproduced here to both comply and make them more legible with the necessary margins for the thesis, etc. The participant information leaflet and consent form for the feasibility study has not been included as to do so would exceed the word limit for the appendices.

Participant Information Sheet; Part One:
Living With and Beyond Cancer.

Introduction
This information sheet describes a study that is taking place at Warwick University to investigate what it means to have cancer. We are inviting people who have had treatment for cancer to tell us what it's like in two ways – by speaking to us about it and by taking photographs that represent what is important to them.

Invitation
We would like to invite you to take part in this research study. Before you decide you must understand why the research is being done and what it would involve. Please take your time to read the following information carefully. (Part 1 tells you the purpose of this study and what will happen to you if you take part; Part 2 gives you more detailed information about the conduct of the study).

Please ask us if anything is not clear or if you would like more information. You are very welcome to talk to others about the study before you decide whether or not you wish to take part.

What is the purpose of the study?
We know that people are now living longer and longer after being diagnosed with cancer. This is obviously a good thing but it can mean people are left with other problems, for example, physical changes causing difficulty or disability, isolation, financial problems, fear of the cancer coming back, etc. A recent study commissioned by the charity Macmillan Cancer Support found that people with cancer think that the impact of cancer on their lives is a very important area of research. There is already a lot of important work looking into

how these problems can be addressed. However, different cancers affect people in different ways and so far, there has been very little work looking into the specific problems that people living in the UK with your type of cancer may have.

This study is therefore asking people who have had treatment for cancer to take part in two interviews and also to take some photos over a short period of time of things that represent how cancer has affected their lives. The photos can be of anything e.g. personal things, family, work, social life, physical changes, treatment, etc. (This will be discussed further with people who decide to take part, if required).

Please note that we are not looking for good photographers! Everybody, including complete beginners, is very welcome. It's about **what** is photographed, not **how** it is photographed. This type of research is fairly new in healthcare but has been used in several areas before, including with people who have had cancer treatment. Photographs can be used to offer a new viewpoint, tell a story or add emotion to a situation. They are a powerful way of shedding light on issues and raising awareness. In social science research they have been found to be very useful for people to explain and add things that may not be expressed in an interview, for example things that are difficult to put into words. We think that using interviews supplemented by photographs will provide an excellent opportunity for researchers and health professionals to learn from people who are actually affected by these issues.

The study forms part of an educational research study.

Why have I been invited?
You have been invited to take part because you have had treatment for cancer and you are able and may wish to take part.

Do I have to take part?
No! You do not have to take part and your usual care will not be affected whether or not you agree to take part. If you would prefer to only take part in some of the study (e.g. interview only or taking photographs only) you may do so. If you decide to take part but then decide you would rather not, you may withdraw from the study at any time.

What will happen to me if I take part?
If you decide to take part you will be asked to sign a consent form which records that you are happy to be involved and have had all the information you need to make that decision.

We will then visit you and talk to you about your life with and after having cancer. This discussion will be recorded. Although we would like to cover certain themes in the discussion (such as what life is like after surviving cancer and whether the 'image' cancer has in society is helpful or unhelpful to you), you will be free to talk about anything that particularly affects <u>you</u>. We will then give you a digital camera and instructions on how to use it (or you can use your own, if you have one and would prefer to). You will be left to take pictures of whatever you feel is important for you and describes life with and after

cancer. Please remember that if you take any pictures of other people, you must have their permission for the photo to be taken and to be used for the purpose of the research. We would like you to also write any notes about the pictures you take or your experience of taking photos.

We can visit you in your own home, at a clinic appointment or anywhere else you would prefer that is convenient for both you and us.

We will contact you by telephone, text or e-mail (whichever you would prefer) to ensure you are getting on OK and are having no problem with the cameras.

After you have had the camera for about two weeks, we will visit you again and you will choose and print 5-10 photographs that you feel best represent living with and beyond cancer for you. We will then have a second recorded discussion about why you have taken and chosen the photos you have and how they relate to your life. This may take us quite a long time and so may require a second visit.

You will be given a copy of the photographs you have chosen and we will keep a copy. These will be held securely and your name or address will not be attached to the photographs. If there are any people on the photographs, their faces can be 'blurred' so that they are unrecognisable.

It would be most helpful to us, if you complete the whole research process but if you only wish to take part in some of the research (e.g. you would like to take photos but not be interviewed), this would permissible.

Finally, you will be invited to a workshop to help us analyse the data that you and other participants have given. All photographs and interviews will remain anonymous at these workshops. It will give you a chance to meet other people who have taken part and collectively discuss the results that are emerging with the principal investigator and actively contribute to the research. The workshops will be audio-recorded and held at appropriate venues but it may be possible to take part by teleconference, if more appropriate for you. If you are interested, we will take your address and send you a letter of interview at a later date.

Expenses and payments
We are unable to pay you for taking part in the research but we are able to re-imburse any reasonable expenses e.g. the cost of a carer while we are choosing photographs, if this is required. Reasonable travel costs to attend the validation workshop will be re-imbursed if agreed with the research team beforehand.

What will I have to do?
You will have to meet a researcher on at least two occasions. You will be expected to take part in two recorded discussions and take photographs of things that represent living with and beyond cancer for you over a period of about two weeks. You will choose 5-10 of the

photos you have taken to represent the most important aspects for you. If you choose to take part in the focus group, you will travel to a venue and discuss the experience of taking part in the research and taking photographs with other participants and the principal investigator.

What is being tested?

We hope to find out what it is like for people living in the UK today to live with and beyond cancer and to find out what their particular issues are. We also hope to find out whether photography is a helpful way to collect information for them.

What are the possible disadvantages and risks of taking part?

There are no specific disadvantages or risks involved in taking part. However, some people may find it difficult and emotional to address the issues that affect them because of their cancer.

What are the possible benefits of taking part?

We do not expect there to be any benefit to you in taking part, although some people find it helpful to think and talk about some of the issues that affect them because of their cancer. We hope, that by taking part, you will help us find out about some of the issues that may affect people with cancer and help us address these for people in the future.

What if there is a problem?

Any complaint about the way you have been dealt with during the study will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making your decision.

Participant Information Sheet; Part Two:
Living With and Beyond Cancer.

What if relevant new information becomes available?

Sometimes we get new information while research studies are taking place which means the way the research is being conducted or the things we are investigating alter. If this happens, we will tell you and discuss whether you should continue in the study. If you decide not to carry on, we may ask you to sign an updated consent form.

What will happen if I don't want to carry on with the study?

If you would like to withdraw from the study you can do at any time, without having to give us a reason why. We will come and collect the camera and wipe the memory card clean with you witnessing it. None of the photos you have taken and none of the things you have said will be used.

What if there is a problem?

If you have a concern or complaint about any aspect of this study, please speak to the Deputy Registrar of Warwick University who is independent of the study:

Ms Nicola Owen, Deputy Registrar, University of Warwick, Coventry, CV4 8UW.

Telephone: 02476 522713; e-mail: nicola.owen@warwick.ac.uk

If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details are available at:

http://www.nhs.uk/aboutNHSChoices/contactus/pages/Howtocomplaincompliment.aspx.

Will my taking part in this study be kept confidential?

If you join the study, the data collected for the study will be looked at by authorised persons from Warwick University. They may also be looked at by representatives of regulatory authorities to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant.

All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves your home or the hospital will have your name and address removed so that you cannot be recognised. Participants have the right to check the accuracy of data held about them.

Involvement of your General Practitioner/Family Doctor (GP)

Because your involvement in this study does not involve any treatment we will not let your GP know that you are taking part.

What will happen to the results of the research study?

We intend to publish the results of the study in appropriate medical and social science journals and present them at appropriate conferences. We may want to publish some of

your photographs too but we will ask your permission first and you can refuse to allow this for any or all of your photographs. You will not be identified personally in any report or publication (unless you wish your published photographs to be accredited with your name as owner of the copyright).

We will keep your hospital or organisation informed of the study progress and will be pleased to let you or your family/friends have copies of any reports, if you would like them.

Who is organising and funding the research?
The study is being organised by the University of Warwick Medical School and funded by the West Midlands Strategic Health Authority. Your doctor will not be paid for identifying you as a potential participant.

Who has reviewed the study?
All research in the NHS is looked at by an independent group, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by a Research Ethics Committee.

The study has also been approved by your hospital or organisation and the University of Warwick.

Further information and contact details
For further details, please contact the researcher leading the study, who is:
Claire Balmer
Warwick Clinical Trials Unit,
Warwick Medical School,
University of Warwick,
Coventry CV4 7AL.
Tel: 02476 151179 or e-mail: C.Balmer@warwick.ac.uk.

Living With and Beyond Cancer: Consent Form

Please initial box if you agree with the statement

- I have read and understood the Participant Information Leaflet parts one and two (Version 1.1, dated 12.10.10).
- I have had the opportunity to ask questions and discuss the study.
- I understand that I do not have to take part in the study and can withdraw from it at any time, without giving a reason why and without it affecting my care.
- I understand that the researchers in charge of this study may close it or stop my participation in it at any time.
- I give permission for my name and contact details to be given to the researchers when I consent to this study.
- I understand that confidential data which identifies me by name may be seen by responsible individuals (such as clinical staff) when it is relevant to my taking part in the study. I give permission for such individuals to have access to my medical records.
- I understand that I will not be identified in any reports or publications resulting from this study (unless I wish my name to accredited to photos I have taken).
- I understand that data collected from me for this study will be stored confidentially and securely.
- I will allow the photos I choose to be used for the purposes of research. I understand that details can be 'blurred' at my request and I can refuse to allow some or all of my photos to be presented or published.
- I understand that the study interviews will be audio-taped.
- I will be invited to attend a validation workshop. If I choose to attend, any contribution and comments I make will remain anonymous.

I agree to take part in this study.

Participant Name (Please Print) ………………………………………………………..…………………………………..

Participant Signature: ……………………………………………………………………………………………………….

Date Of Signature: ……

Witness Signature: ……..

Appendix 4: Photograph reproduction and copyright form

Warwick Medical School
CLINICAL TRIALS UNIT

Photo Reproduction Permission and Copyright Form:
Living With and Beyond Cancer

This form refers to photographs that you have taken as part of the Living With and Beyond Cancer study. We may like to use some of your photographs in presentations and publications arising from the study. Please would you tick and sign statement 1, 2, <u>or</u> 3 below to indicate whether you are happy for us to do this with all, some or none of your photographs. We have attached numbered prints of your photographs to assist you. We won't use any photographs outside the research team without your permission.

☐   1.   I give consent for all my photographs to be reproduced for educational and/or non-commercial purposes in reports, presentations, publications, websites and exhibitions connected to the Living With and Beyond Cancer study *.

Signed..   date...........................

☐   2.   I give consent for photos.. (please specify numbers) to be to be reproduced for educational and/or non-commercial purposes in reports, presentations, publications, websites and exhibitions connected to the Living With and Beyond Cancer study *.

Signed..   date...........................

☐   3.   I do not wish any of my photographs to be reproduced in connection with the Living With and Beyond Cancer study.

Signed..   date...........................

* Your photographs are classified as 'artistic works' and you own the copyright for them. Therefore, you may have your name accredited to any published photographs, if you wish. **However, this may remove your anonymity and the anonymity of people you photograph**. Please tick the appropriate box to say whether you would like to be accredited to your published photographs and sign below.

☐   I would like my name to be accredited to any published photographs I have taken. I understand that this may remove anonymity.

☐   I do not wish my name to be accredited to any published photographs I have taken.

Signed..   date...........................

Appendix 5: Audit trail and coded transcript

I used the CAQDAS software package NVivo8 to assist development and organisation of the coding of each interview transcript, as described in chapter 7 (see diagram 35 for screenshot illustration). Table 14 overleaf shows how I coded a complete interview transcript (30ISp) line-by-line. This was the final interview performed and by then the codes were quite highly developed and themes more easily recognisable, whereas earlier interviews were frequently revisited and recoded as themes and codes evolved. The codes in italics represent those that were eventually amalgamated with others to develop the final key themes (or were occasionally rejected). For example the code 'pets' was amalgamated with the key theme of 'the involvement of family and friends' after discussion with participants who attended the analysis workshops and who felt that pets were part of peoples' 'family' (see chapter 7). I initially allocated more than one code to some lines, either because both were present within a line or I was not sure which was the most dominant. These were reviewed later in the context of all the interviews and photographs. Ambiguous or uncertain codes were prefixed by question marks; again these were reviewed later and, in the cases within the example here, were rejected. Not all my codes are present in this single example. Lines without coding correspond to preamble or conversation that was not relevant to the interview. My voice is represented in bold font.

Following table 14, table 15 shows how I also compared and cross-referenced interviews and photographs to develop final key themes (Oliffe et al 2008), in this case 'reminders'. Please note that these tables represent an iterative rather than linear process.

Figure 35: Screenshot showing part of coded interview transcript 30ISp in NVivo8
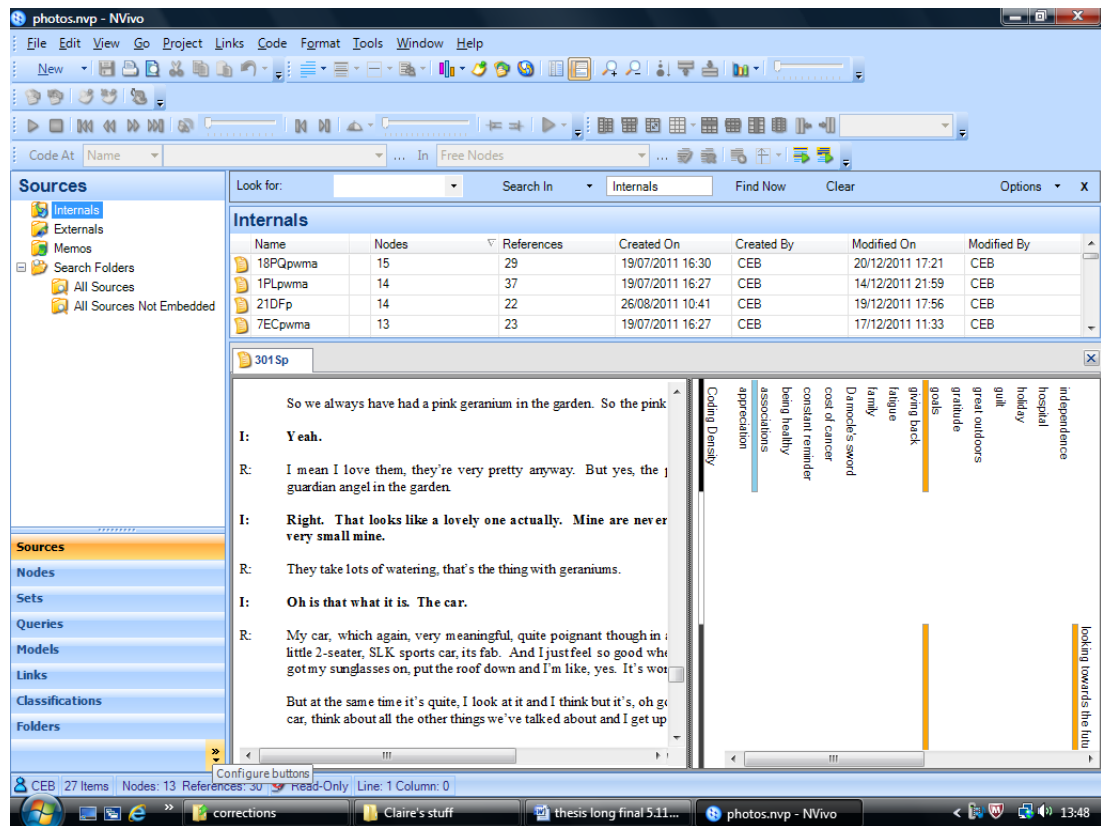
Table 14: Coded interview transcript (30ISp)

Transcribed interview extract	Coding
I could have gone crazy, once I started thinking about it I could have gone absolutely crazy but no, I tried to limit myself	
How did you find doing it?	
It was fun	
You enjoyed it?	
Yeah, I enjoyed it, it was fun but I wish I had a better camera. A friend of mine said you know you should go & get one of these Nikon things with a zoom lens &	
I'm thinking oh blimey, I'm not going to go quite that far. I wish I had got a better camera, because it's not, you know they're not brilliant pictures, they're just	
kind of snaps really but like you say, you're not not supposed to	
Yeah, it's not about being an artist or anything like that	
Yeah, it's about the meaning behind them kind of thing isn't it really?	
That's right	
I think the whole thing has been a little bit like cathartic, it has been a little bit because it's not very often really that you sit & go through the whole process	
from diagnosis to now. So after your last visit, I wouldn't say I was upset by it but it did for the next 24 hours I was thinking about it quite a lot & thinking crikey	Rollercoaster
look at everything that's happened & it's only when you put it together & describe it to a person, like I did with you, that you sort of thing yes actually that's	Rollercoaster
an awful lot that's gone on in the last 6 years & it does sort of hit you a bit & doing the photos the same, it brings it home to you what's important now	New perspectives
& what things you look at differently	New perspectives
Yes, a few people have said that	

Now she's my chemo cat & that is exactly what she is. That's why we call her chemo cat because we got her literally the month before I started my chemo	*Life before/pets*
so all of my days after chemo where I would just be in bed &absolutely pole-axed,	Side-effects/*treatment*
that's exactly what she did; she just sat with me on the bed, wouldn't leave my side, just completely, she was staying with me & if I was on the sofa	*Pets*
she'd do exactly the same. If I sat at the dining table, she would come & sit. She was just by my side, it was like she knew, it was like she had a sixth sense that	*Pets*
something was going on & she was just by my side the whole time & very therapeutic because I think cats are when you stroke them, I don't what it is,	*Pets*
but they're very therapeutic in that way. So we've called her chemo cat.	*Pets*
Do you mind if I just number each of these as well if that's okay with you?	
Yeah & this again is chemo cat & her positioning here was very much sort of laid back in this sort of style & the legs just out, she was actually nearly falling off	*Pets*
there. So yeah the same thing, she's such a laid back cat, that's how she was & that just sums up really that sort of positioning, sums up exactly how she was	*Pets*
& how she's been with me the whole process	*Pets*
It's amazing actually how many people have put animals in, I've found that quite interesting really. Is it the company she gives or peace she represents or	
Yes, that's right company I think & like I say very therapeutic when you're going through something like that & you're feeling ill, they really are comforting,	*Support*
animals, yeah. Now this is my container garden	
That's lovely	
& this is, I suppose this is in because I never was particularly a gardener & after any gardening I did do, I could do quite easily, now after treatment &	*Life before*
everything & lymphoedema in my arm I can't garden the way that I used to. Now everything has to be in a container so that I can actually lift it up on to a table,	Side-effects/limitations
dead-head, best garden I've ever had. Which is ironic really when I say I can't garden anymore because of the restrictions,	New perspectives/limitations
I've now got the best garden I've ever had in my life & it's got to go in, yeah	New perspectives/appreciation

Yeah, you were saying last time about having a smaller patch of garden	
Now this is my little guardian angel. A friend gave this to me & it's just a very nice little crystal, it has pink wings, which she thought was appropriate because of	
the breast cancer being pink & it came in this little box with a little guardian angel message/poem there & it's something which I don't keep & it came in this	*Cancer image*
little box out all the time but it stays in its little box in my dressing table drawer but when I'm having scans or tests or I'm particularly nervous about anything	*Appointment anxiety*
that's going on, then that little guardian angel comes out & sits on the top of my dressing table & every time I look at it I think; no it's going to be okay, my little	*'Touching wood'*
guardian angel is looking over me & she gave me that I suppose within a couple of weeks of my diagnosis & she's a very religious lady, goes to church probably	*'Touching wood'*
about 4 times a week that very religious lady & she prayed, she put me on the prayer list & I've stayed on that prayer list even though I personally don't,	?? Spirituality
I'm not a churchgoer but I am a believer but I'm not personally a churchgoer but she's put me on their prayer list every week for the last 6 years	?? Spirituality
& that's the guardian angel that I just know, it's just there's somebody there, do you know what I mean? So that means a lot to me	Gratitude
So does that represent your friend or something else?	
It represents, I think, to me because it was my friend that gave it to me, it's representative of all my friends that said they're looking out for me, they think of	Gratitude/effects on family & friends
me & every time I'm going for scans everybody sends me messages of support & good luck for it etc. & it just, yeah, that little guardian angel is for me not	Support/gratitude
particularly religious, for her it was but for me it's not you know what I mean? So that's got to stay in.	Support/gratitude
Tell me about this one, what does this mean?	
This is the year after my diagnosis, all the treatments through 2006 & then this was in 2007; I went on a 5 day retreat with Helen Rosen, Cancer Charity & I	Giving back
used to work for them as a volunteer & I went on their retreat & it was to County Donegal in Ireland & it was absolutely beautiful. It was just a house in the	Giving back
middle of nowhere & the beaches were all like this & you just went down the dunes & you walked for miles along these beautiful white, sandy beaches. Stood	Great outdoors
on the top of the cliffs; you could scream your frustration about things from the top of the cliffs, it didn't matter, the seagulls really didn't bother & it was just	Great outdoors

that picture just sums that up. It was a time where, for those 5 days, there was only a group of I suppose about 8 or 10 of us & we spent the five days together.	My space
We did all sorts of complementary therapy things, we learnt how to do Tai Chi & we did all sorts of group sessions, where we had cathartic things going on &	New perspectives
relaxation & meditation & the whole 5 days I came back from it thinking I can do this now, I can move, I can, it was fantastic. It was a 5 day break,	Looking toward the future
best holiday of my life I think.	Appreciation
Were you all sort of similar diagnoses?	
No, we were of all different ages, all different cancers. So yeah & all works of life. There was a couple there; husband & wife, it was the wife with cancer & the	?? 'Club' membership
husband was there as a carer, they lived in Ireland, they were an old couple, must have been about 70 & then there was me & there was a younger lady &	?? 'Club' membership
there was a divorced lady & another guy from, I can't remember what his background was, so we all came from different backgrounds & we all helped support	Support
& complete strangers, none of us knew each other. It was really interesting, so that picture absolutely sums up this sort of looking in to the horizon sort of idea	Great outdoors/new perspectives
& the space & the nature around you. It was just wonderful.	Great outdoors/new perspectives
It looks lovely. Was it a different thing for you to do; different to what you normally do?	
Yes & just what you need having been through all of what I'd been through the previous year & feeling like I'd fallen off the conveyer belt now,	Moving on
what happens next sort of thing? Just got everything in perspective again. So really good	Looking toward the future
I've never been to that part of the world, but I've heard it's just beautiful	
Oh well I hadn't but oh, beautiful, absolutely beautiful; you have to take a raincoat though.	
Right, yeah	
Now this is my bathroom cupboard, which used to contain lots of bits & bobs of makeup & things like my face mask there & my hair thing there & I think that's,	*Life before*
yeah, there's 1, 2, 3, there's 4 things there where that used to be full of just beauty products & makeup & now	*Life before*

it's absolutely full of medications & the bandaging for my lymphoedema arm, all these medications; morphine, pain relief, everything & my bathroom	Side-effects
cupboard is now a medicine cupboard, a whole cupboard for medicine & I just thought that's a huge change that you don't realise has happened	Side-effects/new perspectives
I suppose little things slowly creep in & then you don't realize?	
Yeah, that has slowly gone from now dominating with medicines & only 4 beauty products & it, I suppose, it signifies as well not just the sheer change that my	New perspectives
bathroom cupboard is used for something else but it's the fact that maybe the beauty products now are not as important to me as they used to be & I was	*Life before*/new perspectives
thinking about it as I was taking the photo afterwards, I was thinking there really has been a switch; where I used to sort of pluck my eyebrows, now I don't	Physical appearance/new perspectives
have to because I don't have any. Thank you chemo. You have to really, there's a silver lining everywhere isn't there? My hair grew back but for some reason	Physical appearance/appreciation
my eyebrows never grew back. So little things like that that are not important to me. I don't do all the, my hair just does what it wants & I don't wear a lot of	New perspectives
makeup, I literally just put moisturiser on. Whereas I used to wear, I wouldn't be seen without makeup before & now it's not important & that's indicative in	New perspectives
my bathroom cupboard. I'm not sure if that's a good thing or not though.	*Ambiguity*
Not sure if it's a good thing or not?	
No, I think actually I'm quite pleased that I'm laid back enough to not worry about such things because society does put a lot of pressure on people to look a	New perspectives
certain way & to do certain things & buy certain products & I'm quite pleased in a way that I no longer feel that I have to conform to that.	New perspectives/appreciation
So I think it's a good thing	Appreciation/*ambiguity*
That's number 6. Meerkats.	
Meerkats, now the meerkats thing is my husband brought me those, beautiful little bronze statue & it's him & her & it's all about keeping your head up. He	Soldiering on
brought me that when I was having a bit of down time & he said look if the meerkats can keep their head bobbing up above ground, then so can you & it was	Soldiering on
just a lovely gift & with such a lot of meaning & it just sits there & reminds me every time a get a little bit sorry for myself,	Loss of belief in self

I just look at that & say no, keep your head up	Soldiering on
Is that easy or hard?	
It can be hard but I try to & apart from anything else, it just makes me laugh because I think meerkats are so funny.	Appreciation
So that's why the meerkats are there. That's what I try & do; keep my head up.	Soldiering on
They're very sweet	
This is Mrs Lightbulb. Mrs Lightbulb is my e-bay persona & we signed up for e-bay, well I suppose about the same time of my diagnosis, the first year & it was	
something that my son had suggested. He said you're at home, you're not working because of your chemo, he said you're sitting there, he said you're getting	*Treatment*
bored, he said lets become an e-bay seller. So we did & we started. He went round the house & gathered together, I was shocked at how much stuff he	New perspectives
gathered together, I'm more the hoarder than I realised, so he gathered all of this stuff together, we put it all in a big box & we started selling on e-bay & when	New perspectives
you register to do that, you have to have an ID, a tag or something, whatever they call it but you know what I mean? & so we had to come up with a name for	
us & so he said why don't you use Mrs Lightbulb; it's something he'd always called me from the minute I first lost my hair. The first time I lost my hair	Physical appearance/*cancer image*
the 2 boys had actually helped shave it all off & it was one of the most funny moments, if you can have a funny moment, in all of the cancer thing. I thought I	Appreciation
would be in floods of tears & devastated at the time when actually the hair had gone or I shaved it off, but because the boys both did it. They sat me in the	Physical appearance/*loss*
bathroom, razor in each hand & had brilliant fun for at least an hour giving me Mohicans & all sorts of things, before they finally took it off completely because	Physical appearance/effect on family & friends
most of it had gone anyway. So because of that, when they'd done that, they nicknamed me Mrs Lightbulb because they now said without my hair I now	Physical appearance/*cancer image*
looked like a lightbulb, which is very flattering isn't it? So that nickname kind of stuck all the time that I had lost my hair & so we said well Mrs Lightbulb & we	Physical appearance
managed to find this image of a lightbulb & then [name] very cleverly doctored it & put in the eyes & the nose to make it a kind of a bit of a character & it's just	Physical appearance
stuck so my e-bay is Mrs Lightbulb & it's funny because I've had messages from people who have brought things from us & I've had actually personal messages	Gratitude/support

from them to say how wonderful what you're doing & your son helping & how wonderful that you love your idea & your photo for your profile & everything	Gratitude/support
& giving me messages of support & good luck with the treatment	Support
Right, is that nice?	
Oh yes & these are people, complete strangers & so yeah, that's important because it was a difficult time that was turned in to something positive.	Gratitude/support
A positive time, yeah. That's the photo you showed me last time.	
& that's me & my boy. That's the photo I showed you last time & I just took, I cheated a bit I suppose really because I just took a photo of the photo,	
mainly because [name] is not here at the minute, he's in Australia on a rugby tour. He comes home tomorrow, I can't wait. It's 3 weeks he's been away,	
It's kind of a long time. So I needed to have something of him in here but because he's not been here for me to take a photo of,	
then I've cheated & I've taken that one because that one is very special to me because of him giving me such support when we did	Support
that newspaper interview & it's just, yeah, it means a lot to me that photo	Giving back
That's lovely. So where does he fly in to?	
He's flying in to Heathrow tomorrow & then I'm going with [name] to go pick him up.	
So you're going down are you?	
Yes. I can't wait to see him. He's got his GCSE results today; he took some a year early, so he's taken five.	
Five?	
Yeah he took 5 of them a year early & he's got his grades today but he's a bit disappointed. He got 2 Bs & 3 Cs & the Cs should have been Bs really. So he's a bit	
disappointed I think.	
Can he retake them?	

Well because they're a year early he can just sit them again next year but I think he's a little bit disappointed even though I'm saying you've still got 5 GCSE's.	
The 3 he didn't get were science subjects which he actually wants to do engineering, so he kind of needs the sciences really.	
Well I suppose it's good practice for next year	
It's good practice & it might teach him that maybe revision would be a good idea next time.	
Yes	
& this is my rock, this is my hubby, in his office up above there & I just thought, I don't know, the light was just right & I had the camera because I was loading	Support
the things on to my computer & it was just the way he was framed with the lights either side & he's my rock. He's been absolutely fabulous. He worries himself	Support
silly about me. He hates hospitals. He's one of these blokes that is really just squeamish, can't deal with hospitals or illness or, you know he goes for a blood	Support
Test I have to go with him & hold his hand but he's been by my side very time & he's just been there completely, unquestioning,	Support
he's been fantastic. So he's got to be In there	Gratitude/support
You had to include him?	
Yeah & it's funny because you look at that & your sort of think well wouldn't a husband normally, isn't that what a husband would always do? But I've had	Effects on family and friends
people that I've spoken to that their partners do completely horrible things. I've had one friend of mine that I met on a course & her husband, she'd got	Loss of family and friends
diagnosed & I think she said it was about 7 weeks, he'd left her because he couldn't deal with it. So he left her. You've just been diagnosed with breast cancer	Loss of family and friends
& you've got all this ahead of you & your husband's just up & goes because he can't deal with it. I kind of thought well doesn't every husband do that & then I	Loss of family and friends
remembered her & I thought no, they don't. They're not all there to support you & this is my [name]	Loss of family and friends/gratitude
& your other rock?	
Yeah, my other rock. They're all rocks really aren't they? But yeah, this is my [name] who loves chocolate & I love champagne, as you can see the champagne	

bottle in the background. So this was just a lovely picture because he was doing the ironing & I just thought yeah, he's been wonderful again. I don't know	Support/gratitude
many 23 year olds who do their own ironing, never mind the whole familys' & he will, he will take the whole ironing basket & do that. No questions, no	Support/gratitude
grumbles, no complaints & he's brilliant, yeah & things like because we've got 2 cats, things like the cat litter tray, which, when I was on, I mean I'd do it now	Support/gratitude
but when I was on chemo & infection & risks & so on, he would do all of those sort of horrible, dirty jobs. Again no questions asked. He just got on & did it.	Support/gratitude
So for a 23 year old lad, he's alright	Appreciation
& this is my photo table. A bit past their best actually, but these flowers, again my husband, my rock, he brings flowers for me now pretty much,	Support/gratitude
well not every week, but certainly twice a month he'll come home with flowers for me	
How lovely	
Just for no reason whatsoever & I think that's wonderful & that's, he never used to do that, I mean I did get flowers occasionally on a birthday or anniversary	Gratitude
but it's only since the cancer really that I've thought about it & I've thought yeah, he just shows to me that he's thinking about me quite often & it just, yeah	Gratitude
that means quite a lot & the fact that these are my photos, this is all my family, this is my support network. I look at that table, I like them all on that table	Support
because I look at that table & I think yeah, I can do this, they're all there behind me, supporting me & that's what it's all about really. If I didn't have all of	Support
those then I think I would find it really tough & I feel very sorry for people who have to go through this on their own. I think it must be horrendous. So yeah,	*?? Alone*
that's my support table. Some people have a support group, I have a support table.	Support
That's my pink geranium & that one is doing actually okay at the moment but as I say I'm not particularly a good gardener. They don't always do okay but I've	
always had a pink geranium I've always had a pink geranium & it's a bit of a symbol; pink for breast cancer. Every time my geranium finishes or dies or gets	*'Touching wood'/cancer image*
eaten by the fox or rabbit or something then my husband doesn't leave it more than 24 hours before he'll go & get me another one. We always have to have a	*'Touching wood'*
pink geranium in the garden. So we always have had a pink geranium in the garden. So the pink geranium has got to be in there.	*'Touching wood'*

Yeah	
I mean I love them, they're very pretty anyway but yes, the pink geranium there is a bit like the guardian angel in the garden	*'Touching wood'*
Right. That looks like a lovely one actually. Lots of flowers. Mine are never nice like that, well they're always very small mine	
They take lots of watering, that's the thing with geraniums	
Oh is that what it is? The car	
My car, which again, very meaningful, quite poignant though in a way because I love it to bits; it's a little 2-seater, SLK sports car, its fab & I just feel so good	Appreciation
when I'm driving it especially when I've got my sunglasses on, put the roof down & yes, it's wonderful but at the same time it's quite, I look at it & I think but	*Ambiguity*
It's, oh gosh, I'm going to get upset now over a car, think about all the other things we've talked about & I get upset because of the car.	
Are you okay, do you want to take a minute?	
No, it's alright. I was always promised that for my 50th & I've got it now because we didn't think I'd make 50 so it's kind of, I love it to bits, but at the same time	Goals & milestones/looking toward the future
I look at it & I think that means, I'm quite worried about it because I'm 48 now so I'm thinking okay when I actually have my 50th birthday is that going to be it,	Goals and milestones
is that the time that I'm supposed to go sort of thing? I wanted a SLK but now I've got it I think actually I don't want it because having it means I've got this	Damocles' sword
prognosis, so maybe I don't want it. It's kind of, mentally it's a bit of, it's a difficult one. It means a lot & I've got it & you know it's on your wish list of things to	*Ambiguity/loss*
do before you die & you have all these things, everybody has these, even people without cancer have a sort of, what do they call it a bucket list or something	Goals and milestones
isn't it? So it's always been in my bucket list of what I wanted to have. I wanted a SLK. So it's very, very difficult. It's very much a, not quite sure how I feel	Goals and milestones
about it now. I've had it for 18 months & yeah, I love it to bits, but would rather I had been able to wait until I was 50, do you know what I mean?	*Ambiguity/loss*
I thin so. Yes	
So that's why that's in. Gosh, isn't it funny the things that trigger the lump in the throat? I look at my boys & all of that & I can stay strong	Soldiering on/the effects on family & friends

& then you look at a car & I nearly lose it. It's funny isn't it?	
Yes but like you say the car has got a lot of sort of	
It's got that significance.	
That's right	
Now this, this is my bedroom. I love my bedroom. Absolutely love my bedroom. It's like my house; it's chocolate box cottage & this is all the beams & the 4	Appreciation/my space
poster & I've tried to do it, it's got deep red carpet & then this is my surgical pillow. I thought of all the trouble I went to do the interior design & everything for	Physical appearance/side effects
this room & how lovely it looks because of all the beams & so on & then I've got this blooming surgical pillow which, because of my lymphoedema, I have to	Physical appearance/side effects
have. I have to use that to sleep because of my reconstruction & everything. I find it very hard to get comfortable in bed, because if I lie on that side which is	Physical appearance/side effects
always, of course the surgery is always on the side that you used to sleep on isn't it? It can never be as easy as the other way round. So it's quite poignant	Physical appearance/side effects
again. It's my beautifully designed bedroom, which I'm proud as punch of & yet it's got to have surgical pillow put in there. So again it's a, yeah	Physical appearance/side effects
Yeah	
Because I can't do without the surgical pillow, but it doesn't really go with the design. Not very stylish are they, surgical pillows? Well I haven't actually	Physical appearance/limitations
managed to find one that is but I mean this tapestry bedspread I couldn't get, well I suppose I could maybe try & get some more curtain material & make	Physical appearance
a cover for it but	
I suppose	
But that's going to extremes I think.	
That's great, that's the last one	
Is that all of them?	

Yes, that's it. Is there anything else you think you might have missed?	
No, no I don't think so. Like I said I could have done it forever but I think those are the most important things. The most important things, yes.	
So thank you very much & thank you for all your time. They're really great	
[end of recording]	

Table 15: Example of way in which the final key theme 'reminders' was developed

Example interview data/photographs coded by themes			Examples of related memos made during analysis	Theme	Eventual code reached through iterative process
Example extract from 1st interviews	**Example extract from 2nd interviews**	**Associated photograph**			
[The diagnosis date] has become a birthday now (7.1).	That was on my 40th birthday which is quite a significant milestone in anyone's life but particularly in mine because that was a year after I was diagnosed & for some people, you know, a year after they're diagnosed with that they're not still around. I suppose a birthday was more significant because of the situation (1.2).	Photograph of birthday celebration with friend not reproduced as friend may be recognisable (see chapter 1)	Poignancy of reaching birthdays/celebrations/ seeing seasons turn. Usually happy events but diagnosis date also seen as – sometimes distressing - anniversary. Occasionally anniversaries associated with fear of moving closer to death/recurrence.	Significant dates/time of year *(double-edged reminders - illness/'luck'/ proximity of death)*	**Damocles' sword** (as constant reminder to participants of possibility/ likelihood of recurrence; often leading to self-initiated disrupted biography)
We were in M&S and I glanced at a blouse and [husband] said, "Do you like that? Shall we stop and get that?" and I can remember saying, "Oh no, I was only looking" but inside I was thinking there's no point in spending money because I'll be dead in a year. What is the point of buying new clothes? ... Suddenly your future has gone so all the things that you would normally do thinking that you have a future you stop doing (13.1).	To me my wardrobe is a regular woman's wardrobe, too many shoes and too much stuff all crammed in and there's my wig box and so that really sums it up, the reality that it is still there … I'm still within the five years and so I kind of thought, well I might need it (4.2)		Many description of dread/fear of recurrence. Major -ve effect on future (disrupting biography) e.g. plans delayed/changed, reluctance to invest in future. Constant & not relieved by time (although expectation to be 'free' at 5 yrs – *?? perpetuated by health staff & NHS 'follow-up' process??*)	Fear of recurrence *(and ability to disrupt biography)*	
I can remember her saying she'd beaten it and a year later she was dead so I would never, ever say I've beaten it (13.1).	I've always had a pink geranium and it's a bit of a symbol; pink for breast cancer. Every time my geranium finishes or dies or gets eaten by the fox or rabbit or something then my husband doesn't leave it more than 24 hours before he'll go and get me another one. We always have to have a pink geranium in the garden (30.2)		Linked to 'fear of recurrence' - prevalence of superstitions and practices related to keeping recurrence at bay/not 'tempting fate' e.g. keeping 'lucky' gifts. Link to 'survivorship'.	'Touching wood'	

Example interview data/photographs coded by themes			Examples of related memos made during analysis	Theme	Eventual code reached through iterative process
Example extract from 1st interviews	Example extract from 2nd interviews	Associated photograph			
You just sort of scale down. It's hard but if I'd taken medical retirement then I think I'd have got £6,000 a year so it was just a no-no financially and socially. It was like I could have eaten, I could have survived but all I would be able to do was just sit in the house and survive and pay the electricity bill and you know, I didn't feel that far gone ... I worry about money because I know I can't go and just work and make the money. If I worked full time again I would just work myself into the ground (16.1)	The cost of having cancer! That's what that [photograph] refers to (28.2).	©P Hackett	Financial impact of having cancer - big consideration and worry for many. Examples of participants returning to work before they felt able (especially if single). Ongoing costs many years after treatment e.g. cost of prescriptions for long-term side-effects, hospital parking for appointments, etc.	The cost of cancer	**Financial cost** (and its persistent impact)
I would be quite happy to not work again but I want my pension and I want my lump sum. Not for me, for [my husband] (24.1).	A cancer diagnosis has financial ramifications a long way down the line ... Having recently received my pension forecast at the same time as considering a new business venture which would mean my taking my pension early at 60, this has needed careful thought because of the life insurance aspect. The picture shows me looking at the pension forecast and weighing up the pros and cons (13.2).		Examples of reluctance to change jobs, move house, retire early due to impact on pensions/life insurance/mortgage (for self and others). Also doubts about future employability. ** Strong link to 'fear of recurrence'**.	Future finances *(concerns leading to disrupted biography)*	
My sister entered me into a competition. How I'd fought through the cancer, she'd used that. And I actually won a holiday for six people to go to Ibiza ... Part of the prize they were providing the holiday insurance for everyone but they wouldn't provide insurance for myself (28.1).	My holidays were important to me, to carry on having my holidays and planning something to look forward to but I suppose this highlighted for me all that bit with the insurance and not being able to get cover, which was ludicrous ... it's ripping off people that have got cancer. Even after I had the all-clear, even after five years they would not insure me. Most insurance companies won't insure me at all now (1.2).	© P Larratt	Difficulty obtaining/high cost of travel insurance mentioned repeatedly. Prohibited from engaging in usual 'looking forward' social activities even many years post treatment. Frustration and anger +++ personal loss at hands of corporate business (especially because of illness).	Travel insurance	

Example interview data/photographs coded by themes			Examples of related memos made during analysis	Theme	Eventual code reached through iterative process
Example extract from 1st interviews	**Example extract from 2nd interviews**	**Associated photograph**			
My ex said to me, "Stop calling it cancer. That's a dirty word" (15.1)	That's a picture of my house with my for sale board ... That's my moving on I think and I feel like I need to ... It's kind of like I don't want to sit on that chair because that's where I sat. I don't want to watch those bulbs coming up because that's what happened and that's part of the cancer. I don't want to be in this house anymore (18.2)		Reminders of 'living with cancer' e.g. books read, films watched, walks taken while on treatment – sometimes leading to negative response over positive e.g. flower in bloom previously enjoyed but now disliked due to association. Also cancer associations from others/society leading to negative reminder.	Associations with 'cancer' *Physical objects, metaphors, etc.*	**Constant reminders** (that participants were living with cancer)
I just thought of the effects during chemo. I don't think I fully appreciated that I would have effects that would last the rest of my life. Like one of the doctors said to me, "Swallowing will never be the same for you again and you'll have a dry mouth forever" and I thought, well that doesn't seem so bad, I'll eat soft foods then. I thought having a dry mouth, that doesn't sound bad but when you're living with those kinds of affects they are more real (2.1).	We tend to eat by about 7 and if we're invited anywhere I have to stop eating really at half 8 to let it all go down before I go to bed and what people don't understand is the implications of it, the regurgitating and all of this kind of stuff and so it's easy to say book a table for 7 and that's fine but after that then I'll go but I won't eat ... you haven't got the freedom or the spontaneity to do something late with regards to eating and watching the clock all the time, so that's the significance of the clock (6.2).	 © M Haynes	Day-to-day reminders that participants were 'living with cancer' by ever-present side-effects, physical limitations and related items e.g. contents that must be carried in bags. Often invisible to others, therefore uncomfortable/difficult explanations sometimes needed.	Side-effects and limitations caused by cancer	

Example interview data/photographs coded by themes			Examples of related memos made during analysis	Theme	Eventual code reached through iterative process
Example extract from 1st interviews	**Example extract from 2nd interviews**	**Associated photograph**			
I just genuinely don't like the hospital. I don't like who I've become, the minute I've gone through the door – which is a patient. Which is allowing doctors to dictate what happens to me (24.1).	This is my pile of post. At the moment because I'm on sick pay, or not as the case may be, I probably get two letters a day off them. They always want something. I've spoken to work this morning. I've got to get original sick notes before they'll pay me anything. There's a form called the SFP1 form, I've had to phone somebody else up because I need that form, they haven't sent it to me. In my mind they should have sent it to me anyway. The letterbox is the only thing that talks to me, sort of, "here is some more for you" (21.2).	Photographs not reproduced as participant's name and address shown (see chapter 8): Correspondence related to appointments and meetings with a participant's workplace.	Difficult to escape being a 'patient'. Reminders came from both within health care environment and outside. Can be sociological (e.g. associated with sick role, pay), psychological (e.g. lack of confidence) or practical. Link to 'club membership').	Being a 'patient' *(Participants defined by their diagnosis; a label they cannot shift)*	**Appointments and follow-up** (constant link to 'patient' status).
I got very shaky before appointments because you have to have blood tests and sometimes they keep you waiting for ages because obviously they're dealing with people who don't get good news. It takes time and you're sitting in a grim waiting room with people at various stages of chemotherapy and it was horrible. The first two years were really hard (26.1)	The cancer folder is my folder that I keep everything in related to it so that's all my letters and it's just kind of like, I put it away and I put my CA125 form away in it and then I write my date in the diary that I've got to go and have my blood done. It's like it's a constant ever present reminder of what it was all about and so even now I still go back to my folder (18.2).	Photographs not reproduced as participant's name, address and diagnosis shown (see chapter 8): Blood form for ovarian cancer marker test & montage of letters from hospital.	Follow-up and surveillance leading to anxiety. Constant reminder of disease status. (N.B. see Arthur Frank).	'Appointment anxiety'	
I'm always waiting for it to come back, always. I would only say I have survived it up until now. There would be a kind of caveat and a qualification (13.1).	Not discussed during interview 2.	No photographs (see chapter 8).	Most participants talked of ambiguity of survivorship. Did not relate to 'survivorship' or feel they deserved 'survivor status'. Link to 'touching wood' category.	Survivorship	**The ambiguity of surviving** (liminality)
It's as if you become a member of a club that you didn't ask to join; it's exactly like that (26.1).	Not discussed during interview 2.	No photographs (see chapter 8).	Several participants talked of unwelcome/unsought affiliation to other people with cancer seek. Link to 'being a patient' category.	Club membership	

Appendix 6:

Table 16 Dissemination to date and pending

Date	Meeting	Location	Type of dissemination	Majority audience
September 2009	1st International Visual Methods Conference	University of Leeds, UK	Talk about potential of visual methods and study plans	Academics using visual methodology
November 2010	INVOLVE Conference	Nottingham, UK	Talk about potential of visual methods and study plans	Patients and users
March 2011	Hammer Out Brain Tumours Support Group Meeting	Worcester, UK	Talk about study	Patients and users
April 2011	Health Research @ Warwick Workshop	Warwick University, UK	Poster presentation	Health and social care academics
October 2011	UK Oncology Nursing Society Annual Conference	Glasgow, UK	Poster presentation	Cancer nurses – clinical & academic
November 2011	Institute of Digital Healthcare Conference	Warwick University, UK	Poster presentation	Academics and professionals with an interest in digital healthcare
December 2011	Keele Nursing Research Group	Keele University, UK	Talk about study and early results	Nurses – clinical & academic
January 2012	Cancer52 Meeting	London, UK	Talk about study and early results	Health care staff, third sector staff and volunteers, members of patient & user groups
March 2012	9th Palliative Care Congress	Gateshead UK	Poster presentation (prize winning!)	Health care staff, academics, third sector staff and volunteers, members of patient & user groups

Date	Meeting	Location	Type of dissemination	Majority audience
March 2012	Coventry and Warwickshire Supportive and Palliative Care Meeting	Warwick, UK	Talk about the study and results	Supportive and palliative care staff and academics
June 2012	Midlands Allied Health Professions Research Network	Coventry, UK	Poster presentation	Allied health professionals and academics
November 2012	INVOLVE Conference 2012: Putting people first in research	Nottingham, UK	Exhibition	Members of patient & user groups, health care staff, academics, third sector staff and volunteers
Submitted (awaiting response)	European Journal of Oncology Nursing		Article entitled 'The potential of using participant-produced photographs to explore cancer survival'	Oncology nurses, allied health professionals and academics