

**Setting “Survivorship” in Context:
The role of everyday resources in adjusting to
life after cancer treatment with curative intent**

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Abstract

Background: The number of people living beyond cancer in the UK is rapidly increasing, and their supportive care needs are a pressing issue. Patients treated with curative intent move on to a self management pathway, which uses checklists to measure care requirements. Patients are expected to consider ways of addressing their own psychosocial needs. The focus of care on the quantification of needs and the cognitive strategies used to manage them fails to take the subtleties of patients' social and material context into account. Research suggests that the self management agenda does not adequately acknowledge the challenges of day-to-day experiences of illness, and how people engage with their resources to adapt to life after treatment.

Aim of the study: To explore how everyday social and material resources can be used to adapt to life in the year beyond cancer treatment with curative intent.

Methods: In 2014–15, in-depth interviews were conducted with twenty-six people recently treated for breast, colorectal or prostate cancer (twenty using photo elicitation), followed by seventeen longitudinal interviews approximately six months later. Participants from a range of social backgrounds were recruited through clinics in Yorkshire and the Humber. The method of analysis was constructivist grounded theory.

Findings: Treatment with curative intent is interpreted as turning a curve in life's pathway, requiring gradual reorientation. This is shaped by three processes. In *Responding to diagnosis and treatment*, participants drew on past identities to reinforce their sense of self, and personalised care was crucial. In *Using social resources for meaning-making*, perspectives from the worlds of the family, clinic and workplace contributed to participants' understanding of their situation, and the "survivor" label was rejected. *Developing assets for recovery* involved consolidating the meaning of their illness, negotiating personal change, and using material and environmental resources to regain control, create comfort and chase continuity.

Conclusion: People with good prognoses have a unique outlook on adaptation after treatment. Finding ways of assessing the assets that people do have, rather than what they do not have, is a good starting point for follow-up care. Everyday resources can be used to address three key objectives in adaptation: control, comfort and continuity.

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Declaration of authorship

I confirm that this work is original and that if any passages or diagrams have been copied from academic papers, books, the internet or other sources, these are clearly identified by the use of quotations marks and the references are fully cited. I certify that, other than where indicated, this is my own work and does not breach the regulations of HYMS, the University of Hull or the University of York regarding plagiarism or academic conduct in examinations. I have read the HYMS Code of Practice on Academic Misconduct, and state that this piece of work is my own and does not contain any unacknowledged work from any other sources. I confirm that any patient information obtained to produce this piece of work has been appropriately anonymised.

Chapter 1: Introduction

The challenge in overcoming cancer is not only to find therapies that will prevent or arrest the disease quickly but also to map the middle ground of survivorship and minimize its medical and social hazards.

Fitzhugh Mullan, 1985⁽¹⁾

1.1 Background

Since the American physician Fitzhugh Mullan coined the term “survivorship” in his personal narrative of cancer in the 1980s, research investigating life after cancer has burgeoned. The persistence of physical and psychological effects beyond treatment has been well recognised and documented⁽²⁻⁶⁾. Many attempts have been made to define “survivorship” in a way that works for researchers, policymakers, health care professionals and people with cancer⁽⁷⁻¹⁵⁾. From a policy perspective, the unmet supportive care needs of those living beyond cancer treatment – including psychological, spiritual and informational needs alongside the physical – have become a pressing issue⁽¹⁶⁻¹⁸⁾. More than two and a half million people in the UK are currently living with a diagnosis of cancer⁽¹⁹⁾, and with earlier diagnosis and better treatment high on the health care agenda, this number is expected to rise to four million by 2030⁽²⁰⁾. In the UK, this has brought into focus a potential crisis in the National Health Service, which has not yet established a standardised framework for supportive care for the increasing numbers of people living beyond cancer treatment.

This chapter will outline health care policy issues related to life after cancer in the UK, and will examine current plans for follow-up and some of the challenges to be faced. It will also examine the concept of “survivorship” and prescriptions for how to “do” it that might help or hinder our understanding of people’s experiences after treatment. The discussion then shifts viewpoint, looking through the lens of sociological theory to examine how we conceptualise illness and recovery. It considers how meaning-making and resources shape people’s experiences, how some of these issues remain unaddressed in models of self management, and how this might relate to cancer survivorship. It will conclude by suggesting that our approach to caring for people who

have been treated for cancer currently rests on a top-down, overarching vision of how people recovering from illness can help themselves, and how this vision might benefit from a greater attention to the social context of people's day-to-day lives and how this might affect strategies for adjustment and recovery.

1.2 Policy perspectives on cancer care

The UK's Cancer Reform Strategy⁽²¹⁾ highlighted the need to expand care for cancer patients beyond the hospital setting into the community, and in 2008, the Department of Health, the National Health Service and the charity Macmillan Cancer Support formed a partnership to address this issue – the National Cancer Survivorship Initiative (NCSI). Alongside these efforts, the unmet supportive care needs of people living beyond treatment, including psychosocial issues, became a key issue in the literature^(16, 17). The NCSI is focused on finding an effective approach to care which will offset the increase in pressure on cancer units in UK hospitals.

The suggested strategy, which has been piloted at a range of sites across the UK, is based on stratified care pathways borrowed from the management of long term, or “chronic”, conditions^(22, 23). The pathway is divided into three streams: “supportive and palliative care” for those with advanced cancer that needs specialist management, “professional led follow-up” for those who require ongoing clinical supervision, and “supported self management” for those who have been treated with curative intent and are willing and able to manage their condition at home⁽²⁴⁾. Self management refers to the patient taking responsibility for dealing with the effects of medical treatment, and is a concept that can be applied across all stages of the cancer trajectory⁽²⁵⁾. It is beyond the remit of this thesis to examine self management as an overarching concept, but a consideration of its theoretical underpinnings in chronic illness care⁽²⁶⁾ is crucial in considering how it might be put into practice by people with cancer.

1.2.1 Cancer and the chronic care model

The management of chronic conditions is broad in focus, tackling ongoing symptoms, the side effects of treatment and psychosocial issues in illnesses such as cardiovascular disease and diabetes⁽²⁷⁾. Cancer is now being reconceptualised as a chronic

condition⁽²⁸⁾. This reconceptualisation is far from straightforward – unlike well-defined conditions such as coronary heart disease and diabetes, the term “cancer” refers to a broad range of malignancies with different points of origin, treatments and potential outcomes^(29, 30). It can include periods of acute disease, chronic episodes, long periods with no sign of cancer, or months or years of advanced disease. Where cancer has been treated with curative intent, this might imply, but not guarantee, a possibility of recovery rather than adaptation, unlike chronic disease. The simple dichotomy between “acute” and “chronic” obscures the non-chronic aspects of cancer, and potentially discounts the ways that these might impact on the lives of different individuals⁽²⁹⁾. Tralongo *et al*⁽⁹⁾ characterise the fluctuating trajectory of cancer survivorship as fluid chronicity, acknowledging the possibility of periods of remission, in contrast with the flat (ongoing) chronicity of other long term illnesses.

Cancer patients treated with intent to cure (which removes all detectable cancer cells from the body) are now directed to the self management pathway. Looking at experiences of self management within the chronic care model, evidence suggests that in practice, it has so far failed to take into account the range of micro-level contextual issues which affect individual responses to health problems⁽³¹⁾ – despite its acknowledgement of the role of community-level resources in contributing to health⁽³²⁾. Coulter and Ellins⁽³³⁾ distinguish a further subtlety – that self management refers to the way patients manage problems resulting from their health conditions, and that the actions patients take to maintain their broader health and wellbeing are more accurately described as self care. These two concepts – self management and self care – are inextricably interwoven: managing illness and its consequences at home is a dynamic process contingent on a patient’s physical and social environment, lifestyle, perceptions of wellbeing and capacity to act⁽³⁴⁾. To be successful, self care needs to go beyond encouraging patients to acquire skills in disease prevention^(27, 32) – it requires genuine collaboration between patients and health professionals, and crucially, attention to the context within which patients ask for support⁽³⁵⁾.

The focus of traditional models of care on illnesses rather than on individuals, and the historical legitimisation of expert knowledge above patients’ lived experience⁽³⁶⁾, is at odds with the shift of responsibility towards the individual implied by the self care

agenda. Rogers *et al*⁽³⁷⁾ suggest that the resolution of this tension lies in encouraging a “recursive relationship” (p225) between professional and lay strategies – an ongoing, two-way negotiation between professional and patient to specify, endorse and encourage approaches to maintaining health. This form of partnership working is supported by recent strategic thinking in the UK’s National Health Service⁽³⁸⁾.

The framework for chronic care set out by the World Health Organization⁽³⁹⁾ recognises that managing illness effectively depends not only on health care policy (the macro level), but must also consider the local environment (the meso level) and the resources and perceptions of the patient and family (the micro level). Health care services have to “extend beyond clinic walls and permeate patients’ living and working environments”^(38, p6). Epping-Jordan *et al*⁽⁴⁰⁾ suggest a focus on integrated chronic care models which transcend specific diseases, engaging with people’s everyday strategies for dealing with physical and psychological discomforts – strategies which are affected by a patient’s psychosocial context as well as their symptoms⁽²⁹⁾.

1.2.2 The planning, implementation and evaluation of survivorship care

In the UK in 2003, the formalisation of follow-up was instigated by Department of Health recommendations for a cancer care review in general practice for each patient within six months of treatment⁽⁴¹⁾. These recommendations did not include a standardised template for care, and the review was not taken up in a way which demonstrated consistent improvements. Alongside these initial efforts, a systematic approach to follow-up acknowledging the psychosocial context of patients emerged in the UK, Europe and the USA in the form of Survivorship Care Plans (SCPs), to be completed in secondary care. A variety of SCP templates have been developed^(42, 43), all of which include treatment summaries, strategies for dealing with the physical consequences of treatment, and the measurement of psychosocial needs.

The intention of SCPs is to draw away from a biomedical focus in follow-up (for example, monitoring for recurrence), to introduce an attention to psychosocial concerns and to support self management. A central issue in survivorship care planning is holistic needs assessment – the measurement of patients’ quality of life (QoL). QoL is a measure which represents subjective feelings of physical and emotional

wellbeing. Definitions of QoL in research studies draw on a broad range of variables^(44, 45) – some of these variables are directly measurable (for example, levels of physical functioning), others rely on personal evaluation by the patient (for example, levels of life satisfaction or emotional distress)⁽⁴⁶⁾. Guidance on holistic assessment in the UK commonly focuses on the use of a “Distress thermometer” and “Concerns checklist”⁽⁴⁷⁾ – ways of identifying and quantifying needs. The recommendation is then for health care professionals to identify what the individual can do for him or herself⁽⁴⁷⁾, passing the baton back to the patient.

In studies relating to health, QoL measures are adapted to focus on physical and psychological functioning in relation to disease. Health-related quality of life (HRQoL) is the outcome measure most widely used in cancer survivorship research⁽⁴⁸⁾. HRQoL focuses on physical, psychological and social functioning, but does not encompass the broader societal, cultural and environmental issues recommended for QoL measures by WHO⁽⁴⁹⁾. The use of HRQoL as an intermittent measure, often at baseline (at the point of treatment) and at a second point further into recovery – for example after two years or more⁽⁵⁰⁾ – also leaves a gap in evaluating the experiences of people who are recovering or re-adjusting to everyday life in the first few months after treatment.

1.2.3 The challenges of survivorship care in the UK

The UK’s NCSI survivorship care plan initiative emerged favourably in a recent international review⁽⁵¹⁾, but survivorship care plans are still seen as a work in progress. In UK surveys, the majority of cancer patients report that they have not been offered a written care plan^(52, 53). Early evaluative research into the efficacy of SCPs demonstrated that most show no significant effects on distress or on coordination of, or patient satisfaction with, follow-up care⁽⁴²⁾. Health professionals regard them as resource intensive, particularly in terms of time^(54, 55) – they take between one and four hours to complete with a patient. Brennan *et al*’s⁽⁴²⁾ systematic review of SCPs demonstrates a heterogeneous approach to timepoints for their implementation, with some presented to patients at the point of diagnosis or treatment, and others at a variety of timepoints in the years beyond their diagnosis. Evaluation of the NCSI SCP

demonstrated that creating plans after treatment can sometimes miss issues that could be resolved by providing information from diagnosis onwards⁽⁵⁶⁾.

The UK and the USA have invested in a national strategy for cancer for more than a decade⁽⁵⁴⁾. During this time, an amorphous approach to “survivorship”, which is a phenomenon with few categorisations to help distinguish levels of need between those who are one year, five years or fifteen years beyond diagnosis⁽⁵⁷⁾, has posed further difficulties in developing individualised care. We know little about the differences in patients’ experiences across the potentially long trajectory of living with or beyond cancer. The proliferation of statutory and non-statutory bodies developing follow-up in the UK also expands the time required to negotiate ways of putting ideas into practice: views on who should provide follow-up have been contested⁽⁵⁸⁾. The capacity of specialist services to conduct long term follow-up is limited, and primary care is now seen as the preferred platform for supporting patients on the self management pathway.

Patients prefer specialist follow-up, based on their fear of cancer recurrence and the belief that this can be effectively monitored. When monitoring does occur, many still report a shortfall in expected psychosocial support⁽⁵⁹⁾ – an area of care which GP practices are seen as well placed to address. The workload of primary care has risen sharply during the last decade⁽⁶⁰⁾, however, and there has been debate about whether it can provide the capacity and expertise to successfully manage the large volume of patients who need support across a range of timepoints in the survivorship trajectory^(59, 61). Breaking this volume down into categories within which standardised care can be offered is also a contentious issue. Khan, Rose and Evans⁽⁶²⁾ argue that pinning down a “specific temporal window”^(p35) moves away from service provision that is sensitive to an individual’s diagnosis, disease trajectory and care preferences. With cost effectiveness as a primary policy objective, a balance needs to be struck between the ideal of a bespoke service tailored to individual preferences and a service which is broadly sensitive to micro-level contexts.

1.2.4 Phases of survivorship

Academics adopt varying temporal boundaries for survivorship in order to conceptualise research questions, and have been accused of appropriating the term from patient advocacy groups “to suit their own needs” (Ellen Stovall, president of the US National Coalition for Cancer Survivorship, cited by Twombly ^(15, p1414)). The research agenda focuses on the same ultimate goal as patient advocacy – the understanding and care of people who have been through cancer treatment. Arguments over the appropriate application of the term “survivorship” are unproductive. Khan, Rose and Evans⁽⁶²⁾ suggest that there is no need for a universal label, and that descriptive definitions that are temporally specific (for example, people who are up to five years past diagnosis) are appropriate where they help to operationalise research.

As the practice of stratifying care pathways suggests, specifying more than one temporal window can also be a pragmatic starting point for service provision. Mullan’s concept of survivorship⁽¹⁾ encompassed phases (“seasons”) in the process of recovery, distinguishing between acute survivorship (treatment), extended survivorship (the period of adjustment following treatment) and permanent survivorship (an extended period of time when recurrence becomes less likely). The UK’s National Cancer Survivorship Initiative⁽⁶³⁾ also makes temporal distinctions, separating diagnosis and survivorship into segments: “recovery and adjustment” refers to the diagnosis and treatment phase and up to two years beyond, “early monitoring” spans two to ten years beyond diagnosis, and “later monitoring” begins ten years beyond diagnosis.

Patients in the NCSI’s recovery and adjustment phase, in particular those who have been potentially curatively treated, are suitable for follow-up on the “supported self management” pathway⁽²⁴⁾. The three most common cancers likely to be suitable for this approach are breast, colorectal and prostate cancer (statistics for incidence and one and five year survival rates for these cancers are shown in Table 1, overleaf). Between seventy-five and eighty per cent of breast cancer patients are thought to be suitable for self management one year after diagnosis; the figure is lower for colorectal cancer (forty-six per cent) and prostate cancer (thirty per cent), as patients need more time to develop confidence in procedures which monitor for recurrence⁽²³⁾.

Deaths, new cases and survival rates for breast, colorectal and prostate cancer in the UK

The four most common cancers are lung, colorectal, prostate and breast cancer. The majority of cases are seen in people over fifty, and survival rates for breast, colorectal and prostate cancer are higher than for lung cancer. Breast cancer is the most common cancer in women, and prostate cancer the most common in men. Of cancers affecting both men and women, colorectal cancer is the second most common, after lung cancer.

	Relative survival (%) [*]	
	1 year	5 year
Breast (female^{**})	96	86.6
Colorectal		
Female	73.4	58.2
Male	77.4	59.2
Lung		
Female	35.1	11.6
Male	30.4	8.4
Prostate (male)	94.0	84.8

* Relative survival is a rate that represents cancer survival in the absence of other causes of death; figures are based on the average number of new cases per year between 2013 and 2015.

** Incidence of breast cancer in men is very low, comprising just 0.26% of cases⁽⁶⁴⁾.

Table 1a *Relative survival rates for the four most common cancers⁽⁶⁵⁾.*

	Number of new cases in 2015 ⁽⁶⁶⁾	Number of deaths in 2015 ⁽⁶⁷⁾	Chance of being diagnosed in a person's lifetime ⁽⁶⁶⁾
Breast cancer	55,122	11,442	1 in 8 women 1 in 870 men
Prostate cancer	47,151	11,819	1 in 8 men
Colorectal cancer	41,700	16,067	1 in 19 women 1 in 14 men

Table 1b *Breast, colorectal and prostate cancer: most recent figures for deaths, new cases and lifetime chance of diagnosis.*

Alongside patients' worries about physical issues, psychosocial concerns can be wide-ranging. It is not enough to monitor psychosocial concerns through the measurement of QoL – if patients are to address them, they will need clues about how to do so. There is a choice in how to cater for this – whether to pass the baton on by identifying specific needs and signposting to other organisations, or whether to find ways of communicating principles and effective strategies of self care within a GP consultation. Exploring patients' strategies for recovery and adjustment during the two-year window after primary treatment may be a good starting point for building evidence and advice.

1.3 How to be a model “survivor”

What clues do newly diagnosed patients have to the cancer survivor status which awaits them after treatment? Experiences of life after cancer have been widely conceptualised by academics and patient advocacy groups. The adoption of the term “survivorship” to characterise life after diagnosis across policy, research and advocacy demonstrates that Mullan's⁽¹⁾ survivor metaphor answered a need. Mullan's view was that “patients with cancer...have more in common with one another than they do with people who have not experienced cancer”^(p271). The subsequent diversification of definitions of survivorship suggests that the term may have become too all-encompassing to have a useful application across every lay and professional experience of the disease. As a universal label, “survivor” fails to capture the diversity of lived experience it now represents. It is also a value-laden term which suggests that every patient has faced death and cheated it, that cancer is inherently a battle and is experienced in this way by all patients, and that those who do not survive have failed in some way. While it is a helpful metaphor for some patients⁽⁶⁸⁾, it is unhelpful for others^(69, 70).

1.3.1 What is a cancer survivor?

In the USA, the term “survivor” is commonly applied to anyone who has had a cancer, from the moment of diagnosis onwards. The US National Cancer Institute treats survivorship as a phase between primary treatment and recurrence or the end of life, and also includes family and friends who have been affected by the disease in its

definition of “survivor”⁽¹⁵⁾. The US Institute of Medicine defines survivors as people who have been free of cancer for five years or more, and this temporal categorising is reflected in definitions in other countries, where the concept applies to people living three to five years beyond diagnosis or treatment with no further evidence of cancer in the body⁽⁸⁾. In the UK, however, the Cancer Reform Strategy, the National Cancer Survivorship Initiative and the charity Macmillan Cancer Support include those living with active or advanced disease in their definition of survivor, excluding only those cancer patients who are thought to be at the end of life⁽²⁰⁾.

1.3.2 How do we expect cancer survivors to behave?

Western societies expect a great deal of people who have experienced cancer diagnosis and treatment⁽¹⁰⁾. Academic and lay literature and patient advocacy groups offer a wealth of advice about the importance of adopting beneficial health behaviours – from instigating a schedule of physical exercise⁽⁷¹⁾, improving diet and losing excess weight⁽⁷²⁾, to returning to work⁽⁷³⁾, finding time for relaxation and enhancing spirituality⁽⁷⁴⁾, and finding meaning in the cancer experience⁽⁷⁵⁾. They also suggest that cancer patients should increase their knowledge about their disease and the effectiveness of their communications with health care professionals⁽⁷⁶⁾. Arthur Frank⁽⁷⁷⁾ has described how survivorship, for some, becomes a “craft” – a self-conscious effort to live life with purpose when the illness crisis is over. This calls not only on coping skills, but on the reformation of the survivor’s philosophy of life.

1.3.2.1 Models of survivorship in nursing care

As breast cancer advocate Rose Kushner once pointed out, the effects of treatment and the psychosocial issues which accompany it have traditionally been the territory of nurses rather than clinicians⁽⁷⁸⁾. The literature in cancer nursing has made efforts to define the term “survivorship” using a methodology known as concept analysis. This is based on the premise that a concept can be clarified by naming its definitive attributes. As a methodology, concept analysis has failed to extend beyond the discipline of nursing, and has been criticised for its lack of rigour⁽⁷⁹⁾. What such models from the USA and the UK do indicate is how nurses might perceive their cancer

patients during recovery from treatment, and how these expectations mirror the prescriptions for healthy living advised as part of recovery.

Doyle⁽¹³⁾ offers a patient-centred analysis, viewing survivorship as a process with positive and negative associations, rather than as a fixed status. Key attributes of survivorship include uncertainty, life change (in identity, priorities and relationships), the duality of positive and negative aspects (setting the potential for personal growth against physical discomforts), and individual responses to the “universal” aspects of survivorship. Universal or shared features include the passage through an intense experience, the ongoing nature of the “cancer patient” label, and the distrust of a previously trusted physical body. Doyle’s themes have fluid boundaries which reflect a lack of clarity in the analytic methodology. For example, the effects of bodily changes on intimate relationships appears under both “duality of positive and negative aspects” and “life-changing experience”. The consequences of survivorship are descriptive, specifying only that it affects physical, psychological, social and spiritual health. As a result, the analysis fails to clarify what successful adaptation might involve.

Peck⁽¹⁴⁾ also offers a patient-centred model, drawing on academic literature investigating patient experiences. Rather than prescribing skills acquisition or describing fixed consequences of the survivorship process, it suggests how successful adaptation might emerge. Recovery is dependent upon the survivor’s acceptance of current and past life circumstances, the alteration of their self-image to incorporate the changes brought about by treatment, and the modification of their “future memories”^(p95). “Future memories” is a concept which emerged from the work of Little *et al*⁽⁸⁰⁾, and refers to the meaning we assign to events we have imagined as part of our future – events which may have to be creatively redesigned in the light of the changes brought about by cancer treatment. Peck’s model allows for the feeling of a loss of continuity from life before cancer, and the subsequent reframing of personal identity^(80, 81). It also allows for resistance to the pressure to recover normality or “rejoin the land of the well”⁽³⁰⁾, and for adaptation to new ideas of what is “normal”⁽⁸²⁾.

In Hagan and Donovan’s more recent model⁽⁷⁾, the “self-advocating” survivor lives in a state of hopefulness, owns their symptoms, sets goals, and becomes a skilled information seeker and health-team builder. The model survivor will move through a

developmental process to reach a “new normal”^(p2355) or state of empowerment, which is the preferred outcome of their cancer experience, and survivors who lack learned skills and social support will have difficulty achieving this preferred outcome. This reflects a continued investment in creating “prescriptions for how survivors should conduct themselves”^(10, p596), with the implicit assumption that professional intervention is necessary to ensure success.

1.3.2.2 Finding benefit in the cancer experience

Surbone *et al*⁽⁸⁾ refer to cancer as a word with “toxic connotations”^(p2470). As survival rates rise, public narratives of positivity have emerged as a way of grappling with the “menacing echo” of a cancer diagnosis – referring to the “deeper and more pervasive” shifts in self-image and personal relationships that treatment can bring^(p2469).

Seale^(83, 84) and Bell⁽¹⁰⁾ describe multiple discourses constructing cancer as an opportunity for a “physical, emotional and spiritual makeover”^(10, p584), and point out the prominence of benefit finding and growth as concepts connected with the cancer experience in both research and advocacy. Critiques of this popular conception have pointed out that defining cancer as a life-affirming experience delegitimises negative feelings and can lead to patients feeling isolated or alienated^(80, 85, 86). Segal⁽⁸⁷⁾ refers to the narrative hegemony (the predominant or ruling influence) of positive stories – how they can “act as constraints on the speakable”^(p301), and actively fail to acknowledge the difficulties of illness.

One such discourse is referred to by Sinding and Gray⁽⁸⁸⁾ as “spunky survivorship”^(p147) – an aspirational state of positivity, alongside the deliberate hiding of difficulties to prevent feelings of negativity in others. This is reflected in the cancer narratives of popular self-help literature, which calls on survivors to be cancer warriors^(89, 90) or self-healers^(91, 92), and to overcome, conquer or dance with their disease⁽⁹³⁻⁹⁸⁾. The imperative towards positivity has gripped lay perceptions of cancer recovery through decades, alongside the progress of medical treatments. It is reflected in the patient narratives characterised by Frank⁽⁹⁹⁾ in 1995, which encompass the idea of overcoming cancer to become whole again (the restitution narrative), and the search for benefits in the disease experience (the quest narrative). Frank also described an opposite

extreme: the chaos narrative – the sense of being taken over by cancer, of having no control, of being “sucked into the undertow of illness”^(p115) – and how this may be difficult to voice. This is a narrative which, nearly two decades later, was still seen as “unspeakable”^(87, p296).

1.3.2.3 Acknowledging diversity and context

It has been argued that understandings of the term “survivor” are under-researched⁽¹¹⁾, and that survivorship is an “immature” concept^(13, p499). Evidence from the research quoted above does not support this. Instead, it suggests that the concept does not have the reach that is necessary to encompass the diversity of experience that follows cancer treatment. Tralongo *et al*⁽⁹⁾ call for the use of “nonvalue-laden terms with universally recognised meaning”^(p1). The evidence shows that consensus in the form of universal meanings for those living beyond cancer is difficult to achieve, and its pursuit risks a state of theoretical congestion⁽¹⁰⁰⁾ – the continued burgeoning of descriptive work that reads patient narratives for the same overarching themes and reinforces existing concepts. The search for a single metaphor to represent all patient experience may serve a purpose for policymaking and advocacy. It is less helpful in uncovering strategies for recovery that are particular to the broad range of timepoints and trajectories experienced by people after treatment for cancer.

The implicit expectations in professional and lay language about cancer provide a repertoire of meanings that newly diagnosed patients draw on to construct their experience. In her description of *Illness as metaphor* in 1978, Sontag⁽¹⁰¹⁾ imagined the de-mythicisation of cancer language as potentially curative treatment increased in prevalence, predicting that we would cease to conceptualise every encounter with the disease as a battle or a brush with death. Rather than searching for a single, overarching concept to describe life after cancer, as the experience of treatment and recovery expands and diversifies, the language used to describe it needs to do the same.

1.4 Shifting the viewpoint

For those patients who are asked to walk a self management pathway, physical monitoring for cancer recurrence is only one part of the journey – and an intermittent part. Continuity within the journey is shaped by the psychosocial issues implicit in everyday living. These issues sometimes impact on the health care interventions that seek to address them – for example, Corbett *et al*'s⁽¹⁰²⁾ review of web-based interventions reports that patients chose to drop out as a result of feeling too busy, or having to cope with comorbidities or other family illnesses. Research and assessment using discrete measures of functionality, distress, social support and coping can identify problems and tell us which factors might be associated, but it does not specify how these associations operate. Studies often separate the psychological from the social, reducing this complex interplay of associated factors into discrete categories in order to measure and pathologise or describe and thematise.

In quantitative research, the patient is treated as a case that is “cut out of space and time”, rather than as an individual whose experience is emergent and context-driven^(103, p1630). Studies often focus on patient distress, anxiety and maladjustment^(104, 105), on expectations of care⁽¹⁰⁶⁾ and on the need to promote patient autonomy and self-efficacy^(3, 4, 59, 82). Psychological theories suggest that learning from human experience is not only about acquiring discrete responses to discrete stimuli⁽⁸¹⁾, but also about shifting our viewpoint to examine how complex chains of behaviour link together, and how these chains of behaviour are idiosyncratic and continually reframed within the individual through contact with the environment and with other people⁽¹⁰⁷⁻¹¹⁰⁾. Medical sociology has further contributions to make in this area.

Sociological research examining lay perspectives on health and illness recognises that the role of life history, environment and social relations can be captured in the narratives that people construct about their experiences:

The importance of seeing lay knowledge in its narrative form...is that it provides a different perspective on the relationship between individuals and the places, or “relational settings” in which they live. This perspective makes “place” more than a set of static environmental

deficits or provisions, no matter how imaginatively these are operationalised, and it makes the “lifecourse” more than a biological trajectory during which the individual is inertly exposed to various accumulating risks or benefits. It highlights the need to look not just at the statistical associations between significant events in people’s lives as defined by researchers, but at the meanings people give to the relationship between these events—how they translate events into meaningful episodes. Popay et al, 1998 ⁽¹¹¹⁾

Studies examining the links between social context and health suggest that the privileging of individual, rational action implied by the self management agenda fails to acknowledge the fundamental concerns and challenges that people face in their day-to-day experience of chronic illness, and the meanings that they make out of these experiences⁽¹¹²⁾.

1.4.1 Sharpening the focus: the theoretical lens

How do we explore the fundamental concerns about psychosocial issues in follow-up care without replicating the wide range of research already carried out into patients’ narratives about cancer? The debates discussed above suggest two clear avenues: taking a clearer focus on specific timepoints in the survivorship trajectory, and moving away from prescriptions about “good” survivorship to examine the recovery from cancer treatment in the context of day-to-day life. In preface to a review of existing literature on adjustment and/or recovery after cancer treatment, a brief outline of the major threads of theoretical thinking in this area will help to suggest ways in which research can build on existing knowledge and avoid starting anew.

A focus on recovery calls into play another subgenre of narratives⁽¹¹³⁾ reflecting the prescriptions for positivity described above. Recovery narratives currently focus on polarised responses to illness, reflecting the transformation required from this process as a movement from one extreme to another – from dissatisfaction to fulfilment⁽¹¹⁴⁾, from “chaos” to “restitution”⁽⁹⁹⁾ or “restoration”⁽¹¹⁵⁾. Rather than continuing to build on these polarised concepts, mapping the middle ground (following Mullan’s call about

survivorship at the head of this chapter) might begin to diversify our exploration of different cancer survivorship trajectories.

Barbour⁽¹¹³⁾ and Rose⁽¹¹⁴⁾ trace the drive towards positivity as emerging from the requirements of the “biographical project of self-realization”^(114, p*x*), a sociological concept also characterised by Giddens (and later by Frank) as “life-planning” – “a means of preparing a course of future actions mobilised in terms of the self’s biography”^(35, p85). This interweaves with theories about chronic illness, ideas from which are now being borrowed to inform cancer follow-up (see section 1.2.1, above). Chronic illness has been theorised as a phenomenon that interrupts the self-realisation project – as biographical disruption⁽¹¹⁶⁾, a dilemma of identity which is resisted through strategies of self preservation⁽¹¹⁷⁾.

The concept of biographical disruption has been challenged for its lack of attention to the mediating role of “social patterning”⁽¹¹⁸⁾ – the circumstances within which it occurs. For example, there is a difference between an experience of chronic illness that begins at birth and the emergence of illness via a period of transition during adulthood. There can also be a difference in attitudes towards life-planning between people who are affluent and deprived – in impoverished circumstances, the hardships of illness are sometimes viewed as a normal part of life rather than as a crisis that requires the reframing of a life plan^(119, 120). Of the conceptual models of survivorship offered above (see section 1.3.2.1), only Peck’s⁽¹⁴⁾ is flexible enough to accommodate cancer as a non-disruptive event. Williams⁽¹¹⁸⁾ also points out that in lay terms, biographical disruption does not always emerge *from* illness – it is often seen as a precursor or cause of ill health.

Williams⁽¹¹⁸⁾ also discusses the role of meaning-making and setting (circumstances) in responding to illness – that it requires a “mobilisation of resources” that are already available to the individual, and that these resources are “physical as well as social, temporal as well as financial, medical as well as cultural”^(p43). Drawing on Bury⁽¹²¹⁾, he suggests that the meaning of illness encompasses its symbolic significance as well as its practical consequences. Our level of commitment to an anticipated future is deeply interwoven with “*timing and context, norms and expectations*”^(p51) (Williams’ italics), and these issues and the subjectivities connected with them determine our need or

capacity to adapt to, or recover from, an alteration in circumstances. These concepts build further on the missing contextualities highlighted by critiques of models of self care^(31, 122).

The fluidity of cancer chronicity described above⁽⁹⁾ suggests that shifts in meaning-making and periods of readjustment may occur more frequently in cancer than in chronic conditions. Looking at self care from the theoretical viewpoints outlined above, the role of social context in creating limitations and possibilities for adaptation and/or recovery cannot be ignored – currently, we fail to operationalise social context in a way that captures its subtleties. The failure to take these subtleties sufficiently into account is likely to affect the success of follow-up interventions.

1.5 Chapter summary

The policy perspective on cancer care is currently focused on the unmet needs of the growing number of people who survive beyond cancer treatment. The UK is beginning to create a systematic strategy for follow-up services, borrowing the concept of self management from chronic care as a way of encouraging adaptation and recovery in those who no longer require intensive specialist support. The World Health Organization emphasises that successful self management will be contingent on patients' social, environmental and material circumstances, and that these circumstances affect perceptions of illness and the capacity to act on these perceptions. This is supported by sociological theories examining chronic illness and self care. The patient perspective on living beyond cancer is currently dominated by narratives framed to fit the aims of patient advocacy, research and policy: these prescribe the best way to enact "survivorship", and pay little regard to the mediating role of pre-existing social and structural resources in people's desire or capability to be a "good" survivor. The remit of survivorship research needs to include exploration of the role of such resources in adaptation and recovery. Given the expanding trajectory of "survivorship" over longer periods of time, addressing specified timepoints in this trajectory might be a sensible way forward in examining the uniquely fluid chronicity that characterises cancer.

Chapter 2: Literature review

Every ache and pain I have I think, hmm, wonder what this is...I feel like an unattached buoy in a large body of water, because when you're in chemo you feel like something is killing it, but now I'm on my own. I'm out there...I feel a little bit like a buoy in rough waters. I feel like I get thrown around a little bit by the waves of life, you know, and it's scary for me that way.

Breast cancer patient "Lisa", in Kaiser, 2008⁽⁸⁶⁾

2.1 Introduction

The large body of research papers investigating life after cancer treatment includes clinical descriptions of cancers and therapies, the quantification of unmet physical and psychosocial needs, evaluations of interventions, and qualitative studies of the experiences of patients and health care professionals. The diversity of cancer as a disease adds further complexity to the field, with some studies investigating cancer by type (defined by its primary site in the body), others looking at generalised characteristics of cancers across multiple sites.

The following review focuses on the key issues arising in qualitative literature exploring patient perspectives on adaptation to life after cancer treatment. The focus on qualitative research derives from the epistemological standpoint of this study outlined in Chapter 1: qualitative methods are appropriate for investigating the complex interplay of contextual issues that bind together patients' experiences – phenomena such as distress and social support, which are reduced into measurements in quantitative research. Chapter 5 (*Methods*) will explore this standpoint in more detail. This study considers a specific timepoint in the cancer trajectory: the year after treatment. This review was undertaken to examine what existing qualitative research reveals about the range of experiences a patient might encounter during this time. Cancer is diverse not only in its point of origin, but also in its stage and severity: given that this project considers people who have been treated for primary cancers with curative intent, the search was restricted to papers considering primary cancers.

The chapter begins by outlining the search strategy and aims of the review. It then considers the theoretical concepts used by the included studies to approach and interpret their data. These are summarised under two concepts – coping and cognition, and meaning-making. The five key topics explored in the literature are then explored: information and communication; spirituality; cultural differences; sexuality, intimacy and reproductive issues; and the return to work. The chapter ends by discussing the limitations of the literature, and considers what might be missing in our exploration of patient experiences in the year after potentially curative treatment for cancer. It ends with a statement of the research questions for this study.

2.1.1 Search strategy

A broad strategy was adopted, initially, searching the electronic databases MEDLINE, Embase, CINAHL and psycINFO and ASSIA. The search was first performed in 2014, and updated in 2018. The initial search used the terms cancer*, tumo?r, neoplasm* and malignan* to retrieve research studies in English about cancer. The retrieved articles were then used as a basis for two separate search strands: one using a title search for the term meaning*, to retrieve theoretical articles and research studies on meaning in the first twelve months following diagnosis or treatment, and a second multi-field search to retrieve qualitative research articles examining patient experiences in the twelve months following diagnosis or treatment.

In the second stage of the search, a qualitative keyword filter⁽¹²³⁾ was applied to these articles, using the terms qualitative, interview*, narrative*, phenomeno*, grounded?theory, discursive and discourse* to retrieve qualitative studies. The results of this search were refined by combining them with four separate title search strings using the following terms:

- adapt*, recover*, cop* [coping], transition*
- post?diagnosis, post?treatment, “after diagnosis”, “after treatment”, “following treatment”
- psychosocial
- cure, curative*

The results of these searches were combined and duplicates removed, leaving 6,362 papers. The focus on cancer treated with curative intent led to the exclusion of articles considering only cancers with median survival times of up to five years – including cancers of the kidney, ovary, stomach, oesophagus, pancreas, brain and lung, adult leukaemia, and myeloma. Papers including these cancers were retained where at least fifty per cent of the sample was made up of people who had experienced a cancer with a median survival time of more than five years – cancers of the breast, colon, rectum, prostate, cervix, uterus, testis, larynx or skin, or the blood cancer lymphoma. Papers focusing on metastatic or advanced cancers were excluded. Books, dissertations and grey literature were excluded for practical reasons, given the volume of literature available; selected relevant grey literature is outlined in Chapter 1.

This left a total of 476 papers, the abstracts for which were searched through by hand. Articles on perspectives other than those of patients (e.g. health care professionals, caregivers or spouses) were excluded, except where they included corresponding patient perspectives. Articles on paediatric and adolescent cancer were excluded, as were articles evaluating interventions. Articles focusing on experiences of treatment or including only patients currently in treatment, rather than adjustment to life post-treatment, were also excluded. For the purposes of this review, post-treatment is defined as the period after completion of surgery, chemotherapy and/or radiotherapy, and does not include ongoing adjuvant therapy such as hormone medication.

Papers including patients who were more than a year beyond treatment were included where more than fifty per cent of the sample were a year or less post-treatment. These included articles examining experiences of adaptation during part or all of the twelve months following treatment. Sampling of participants at an exact timepoint twelve months beyond treatment did not always occur as intended in the studies⁽¹²⁴⁾, and the decision was made to include articles focusing on experiences spanning the first two years that did not distinguish a specific timeframe for the first year. A total of fifty-one qualitative papers considering patients' experiences of adjustment in part or all of the year after treatment for a primary cancer were retrieved. These papers are picked out in bold in the *References* section (pp279-84).

Barbour has outlined the methodological difficulties of using quality checklists in qualitative research⁽¹²⁵⁾, and Dixon-Woods *et al*⁽¹²⁶⁾ have demonstrated that agreement on quality criteria is difficult to reach. Papers for this study were screened for quality, but the review aimed to be inclusive – all studies touched on empirical concepts of relevance to patients’ experiences of adaptation, and none were excluded on the basis of quality criteria. Good quality papers contributed novel insights to the themes and substantive areas considered in this chapter; papers of poorer methodological quality were more likely to reiterate themes that appeared in other papers, and to explain them in less detail.

2.1.2 Aims of the review

The literature review aimed to investigate the following issues:

- What theoretical frameworks are used in the research literature to interpret patients’ experiences in the year after cancer treatment?
- What are the key topics considered by researchers in examining patients’ experiences in the year following treatment for a primary cancer?
- What are the limitations of the literature in this area, and what questions could be asked to begin to address the gaps in the literature?

2.2 Setting the scene: theoretical frameworks

This section explores the two theoretical approaches most commonly quoted in the literature considered for this review: coping and cognition, and meaning-making. The concepts highlighted below summarise the ways in which the psychological and social behaviours of patients are characterised in research studies. *Coping and cognition* focuses on individual psychological strategies (individual coping) and on how these might be mediated by social interaction (relational coping). *Meaning-making* focuses on theories drawn from existentialism, on the widely used concepts of identity and biography, and on definitions of illness – in particular, on definitions surrounding the concepts of chronicity and cure.

2.2.1 Coping and cognition

The most ubiquitous framework for exploring patients' experiences in the year after cancer treatment is the concept of coping. Where stress and coping theory is used to characterise the year after cancer treatment, studies focus on stress management strategies from an individual or relational perspective. Individual approaches are intrapersonal (based on cognitive processes within the individual), relational approaches are interpersonal (based on interactions with others).

2.2.1.1 Individual coping

The model of stress and coping developed by Lazarus and Folkman⁽¹²⁷⁾ is the most popular framework used to examine the discomforts brought about by cancer diagnosis and treatment, and understanding how individual behaviour contributes to adaptation⁽¹²⁸⁾. Stress is defined as an imbalance – when the demands placed on a person exceed their resources for coping. It emerges from a process of appraisal, when the elements of a threat are evaluated for their personal significance and effects on wellbeing, and options for changing undesirable situations are reviewed⁽¹²⁹⁾. These options can be internal (psychological strategies such as exercising will power) or external (environmental resources such as social support), and can focus on addressing a problem (problem-focused coping), or on ameliorating the negative emotions that accompany it (emotion-focused coping). Complementary theoretical perspectives based on cognitive adaptation within the individual focus on similar issues such as threat appraisal and goal setting, and the role of self-efficacy in effective coping⁽¹³⁰⁻¹³²⁾.

The literature framed by coping and cognitive adaptation theories is grounded in patients' descriptions of their sources of distress and how these are accommodated. These include managing the physical and psychological changes that treatment brings. The effects of treatment may make leaving the house difficult, for example in the case of incontinence after prostate or colorectal cancer treatment^(133, 134) or when difficulties in eating arise where surgery for head and neck cancer has affected the palate⁽¹³⁵⁾. From a psychological viewpoint, treatment can bring the sense of a loss of control, and with this, a feeling of being overwhelmed by changes in everyday life –

and by information and advice about potential cancer-related experiences and their management^(136, 137).

The literature reflects a focus on positive attitudes as the best approach to adjustment. Positive strategies include efforts to enhance the “normal self”⁽¹³⁶⁾ – for example, through minimising problems by making comparisons with others who are worse off, through finding benefit in the cancer experience⁽¹³⁷⁾, or through engaging in altruistic activities⁽¹²⁹⁾. Problem-focused approaches are construed as laudable: learning to live with physical symptoms, having an upbeat mental attitude in the form of resilience or fighting spirit, and reappraising expectations^(133, 135, 138-140). The set of skills required for positive adaptation include the ability to set (or rework) goals^(141, 142). Foster and Fenlon⁽¹⁴³⁾ demonstrate the value of goal setting in decreasing physical and psychological symptoms, but point out that a level of confidence is required to exercise such strategies, and that this is not in evidence in every patient. McSorley *et al*⁽¹³³⁾ emphasize that positivity is not an automatic, unmediated response to the crisis of disease – it is gradual, emerging from “rationalization”^(p633) – a process of thinking through and deciding what is important, or making meaning from experience.

2.2.1.2 Relational coping

Studies framed by stress and coping theory fall in line with models of survivorship that centre on the individual. The role of other people is acknowledged without making relational issues a central focus, and as such, these papers have limited scope in describing the interpersonal aspects of adaptation. It appears in the form of themes covering social support that are largely descriptive, pointing out the role of spouse and family in practical issues such as travel for treatment and caring activities such as cooking and supportive talking⁽¹³³⁾. Illingworth *et al*⁽¹⁴⁴⁾ argue that the focus on the intrapersonal in studies of adjustment and coping creates a one-dimensional view of patient experience and results in a lack of context. People locate and make sense of their experiences in relation to significant others, and interaction within families can make cancer a cooperative effort.

A subsection of the literature takes a deliberately relational perspective towards coping and adjustment in the months after treatment, examining recovery from

the perspective of dyads (patients and a partner or close caregiver)⁽¹⁴⁵⁻¹⁵⁰⁾ or families^(144, 151). The consideration of dyadic coping between romantic partners is largely seen in a positive light: couples merge strengths⁽¹⁴⁷⁾, develop common goals⁽¹⁴⁶⁾, and renew their commitment through dealing with cancer as a partnership⁽¹⁴⁹⁾. Illingworth *et al*'s study expands the viewpoint to consider family relationships⁽¹⁴⁴⁾: wellbeing is calibrated between family members, rather than within the individual. This study, based in Scotland, conceptualises families as possessing a group identity or culture with a collective drive towards maintaining balance and harmony. This is reminiscent of themes presented as distinctly non-Western in literature based on other cultures. Simpson's Hong Kong study⁽¹⁵¹⁾ takes interrelatedness a step further, situating family culture within broader national culture and demonstrating how family perspectives are affected by cultural and spiritual beliefs surrounding illness (for further discussion of cultural issues, see section 2.3.3 below).

In literature considering Western cultures, families are represented as less situated within wider cultural mores. It is difficult to distinguish whether this is an artefact of the research approach, as broader contextual issues that might be an influence are not well explored in studies with predominantly white participants – the individual, the caregiving dyad and the family are considered as units within themselves, rather than in relation to wider society. A different approach is taken in studies of African American women with breast cancer – studies by Sterba *et al*⁽¹⁴⁵⁾ and Morgan *et al*⁽¹⁴⁷⁾ focus on social and spiritual networks, describing a strong impetus towards disclosure and sharing that is less evident in studies with no specific cultural focus.

The role of other people in the experience of cancer is also included in the studies reviewed here as a way of explaining extra stressors. Interactional stresses are evident within the family unit – cancer can create waves of reciprocal suffering in those close to the cancer patient^(128, 152, 153). The person with cancer may have to engage in emotional labour to protect family and friends from stress and maintain their support^(129, 136, 138, 152) – this involves a level of self-regulation to minimise expressions of fear or anxiety⁽¹²⁹⁾, and can lead to feelings of isolation⁽¹⁵⁴⁾. Isolation can also be experienced where treatment causes functional difficulties or differences in appearance that inhibit the resumption of social life⁽¹³⁵⁾. Cancer treatment can

also compromise familiar family roles (for example, the “patient” role might involve adjusting to a loss of autonomy and a relinquishing of other responsibilities), or introduce transitory roles (such the sick role⁽¹⁵⁵⁾, or the carer role), which are lost when treatment comes to an end⁽¹⁴⁶⁾.

From a dyadic viewpoint, partners’ feelings of wellbeing affect those of the patient, and vice versa⁽¹⁴⁴⁾. Embodiment issues can have psychological ramifications – for example, between partners who are facing changes in sexual function after treatment, taboos can develop around discussions about intimacy^(133, 137). With the exception of issues surrounding sexuality, evidence of not-supportive romantic relationships is rare – all though it is touched on by Ohlsson-Nevo *et al*⁽¹⁴⁸⁾, who describe patients’ partners remaining aloof from cancer, “living parallel lives”^(p560). Closeness can depend in part on a patient’s willingness to share their experience.

Friendships are not considered in isolation in the literature reviewed here – close friends are occasionally represented in carer dyads, but these relationships are explored in the context of the friend’s role as caregiver, in the same way as family members. Friends are included in broader perspectives of social support: not all friends provide what Beatty *et al*⁽¹³⁷⁾ refer to as “cold weather” support^(p338), and some friendships are lost as people emerge from treatment. All relationships make demands, regardless of a person’s level of need: being a good cancer patient involves a display of stoicism (whether or not this strength is genuinely felt)⁽¹³⁷⁾, and this outlook might be more easily traded for support than a display of difficult emotions.

2.2.2 Meaning-making

The meanings and metaphors attached to our experiences provide ways of working out how to behave^(156, 157) – for example, if disease is imagined as waging war on the body, we have a choice of whether to fight or to surrender. The literature described above, framed by coping theories, takes a fire-fighting attitude towards recovery: it focuses on efforts to extinguish distress. The literature considering meaning-making examines how patients conceptualise their cancer experience, and how this affects their behaviour. Researchers use a range of theoretical categories to examine patients’ meaning-making – the primary approaches in the literature considered for this review

can be summarised under four headings: existentialism, identity, biography and definitions of the disease. The concepts of existentialism, identity and biography are permeable, to an extent – where they are used to frame research studies, they often overlap. This crossover is considered further below, in section 2.4.3.

2.2.2.1 Existentialism

Philosophers who have written about existential issues do not recognise the term “existentialism” as a concept which can be defined through their work⁽¹⁵³⁾ – it is a broad term referring to our consideration of the challenging aspects of human existence such as freedom, choice and mortality. In work related to cancer, existential terms offer ways of characterising the challenges presented by the disease. The literature considered for this review calls mainly on four existential concepts described in the 1980s by Irvin Yalom⁽¹⁵⁸⁾: death, freedom, isolation and meaninglessness. In existential terms, thinking about these issues provokes anxiety which we seek to alleviate through our behaviour. Yalom’s four themes are considered separately in this section.

The association between cancer and death has emerged from its potential to be life-threatening, and from the difficulties scientists and clinicians have experienced in understanding and combatting the disease⁽¹⁵⁹⁾. The association with death remains present in recent literature on patient experiences, suggesting that advances in treatment and survival have yet to make a mark in the public consciousness. Cancer diagnosis makes awareness of the possibility of death keener^(86, 128, 134, 137, 147-149, 151, 154, 160-164), and knowledge of the deaths of others from cancer makes this awareness sharper still^(86, 152, 165, 166). People with a cancer diagnosis counter fear of death with a focus on positivity and growth^(137, 148). Landmark, Strandmark and Wahl⁽¹⁶⁷⁾ describe patients imagining death as a replacement for their future – this thought provokes strength and a “will to live”^(p115). Thomé points out how the fear of death is mediated by age, when the mode of dying becomes the focus of fear rather than death itself, which is perceived to be closer and easier to accept⁽¹⁶⁸⁾.

The existential concept of freedom is explicitly described in just one paper⁽¹⁵³⁾. The openness or uncertainties of life, and the responsibility of making choices (our

“authorship” over our own lives), make us anxious. Cancer brings uncertainty. Has the disease been removed from the body, or will it recur?^(86, 128, 129, 134-136, 162, 163, 169-171) What should I do?^(137, 138, 143, 162) Is a reorganisation of life priorities required?^(135, 142, 147, 149, 153, 164, 172-174) The salve for the anxieties stemming from freedom of choice usually comes in the form of externally structural frameworks – the organisation imposed on our life by other people and agencies. But cancer treatment steals away the structure of everyday life, taking away familiar domestic or work routines^(137, 161, 174, 175), and replacing them with a clinical regime – a temporary scaffold that is lost on the completion of treatment^(129, 137, 169). Returning to work can set helpful boundaries around some of the uncertainties stemming from treatment⁽¹⁷²⁾.

Isolation is experienced at the point of diagnosis, on becoming different from others through the transition from health to illness^(143, 154, 165) or through the uniqueness of symptoms in comparison to those of other patients⁽¹⁵³⁾. Where the effects of treatment make eating and drinking or digestion difficult – for example, as a result of surgery for head and neck cancer⁽¹⁷⁶⁾ or colorectal cancer⁽¹⁷⁵⁾ – inhibitions can develop around socialising. Where isolation pre-exists cancer, it can persist – for example, among immigrants who do not speak the language of their country of residence⁽¹⁶³⁾, or among older people who live alone⁽¹⁶⁸⁾. Where it stems from the cancer experience, it can be self-perpetuating when adjustment is not successful – stoicism and rumination on fears and difficulties can shut down prospects of sharing the experience⁽¹³⁶⁾. The strongest anchor against the anxiety of isolation is the quality of social support, in particular from the family, from a religious community, or from continued contact with the workplace^(145, 153, 173, 177).

Meaninglessness is a sense of a loss of coherence and purpose in life^(136, 153). Yalom⁽¹⁵⁸⁾ points out that we are free to make our own meaning, it does not exist independently of us – and that this circularity between freedom and meaning provokes anxiety. The search for meaning is a ubiquitous theme in the literature in the year after cancer treatment, but is not often set in a theoretical perspective. Ching, Martinson and Wong⁽¹⁶⁰⁾ and Lagerdahl, Moynihan and Stollery⁽¹⁵³⁾ refer to the work of Park *et al*^(178, 179), who conceptualised meaning on two levels: global and situational. Global meaning “encompasses a person’s enduring beliefs and valued goals”^(178, p116), emerges

from collected experiences over time, and influences interpretations of the past and present and expectations for the future. Situational meaning is how we make sense of an event or experience – this can either sit well with our global meaning or feel incongruent. It is this incongruence that leads to rumination, distress, and difficulties in coping.

Park *et al*⁽¹⁷⁸⁾ define cancer as a severe stressor that can “shatter” global meaning systems^(p864). The literature reflects this strong terminology. Diagnosis brings a state of chaos^(160, 174) – a disordering of events and frameworks of thinking. The reordering of thoughts is achieved by framing new meanings around the event. The anxiety of meaninglessness is challenged in many ways in the year beyond cancer treatment. The cancer experience can be assigned metaphors which transform it into a phenomenon associated with a particular response – for example, it can become a fight against something unnatural, or it can be yielded to as part of the natural course of events⁽¹⁶⁰⁾. Illness itself can be given meaning through spiritual thinking – seeing its purpose as part of God’s plan^(145, 177) or as a sign that life should be lived differently⁽¹⁷⁵⁾. A sense of purpose can also be found through continuing to work^(140, 161) or through altruistic activities^(86, 153). Meaningful activities include undertaking short term tasks that bring a sense of strength⁽¹⁶⁷⁾ or creativity^(167, 175), and activities that are pleasurable^(128, 147) or purely hedonistic⁽¹⁵³⁾ – Picard *et al*⁽¹⁴⁹⁾ refer to this as “safeguarding zones of wellbeing”^(p123).

2.2.2.2 Identity

Identity and how it is affected by illness has been theorised broadly in health research, and this is reflected in the papers included in this review. Charmaz’s theory of identity work in chronic illness^(115, 117, 180) is drawn on to describe how the unity between body and self is lost when physical capabilities are lost^(86, 143, 146, 165, 173, 181). The concept of lost identity is also drawn on in papers with no specific theoretical perspective – for example, Martin *et al*’s⁽¹⁶⁴⁾ study identifies “losing myself” as a thematic strand in war veterans’ narratives about cancer, and Ching, Martinson and Wong⁽¹⁶⁰⁾ describe how participants need to sustain a sense of self throughout treatment.

Patients view bodily changes and compromised physical abilities during treatment as processes that can steal away their identity^(143, 164, 165, 181). As the discussion of existentialism, above, points out, the disruption of routine brought about by physical changes can pull everyday activities out of shape, and the sense of identity or “self” embedded in familiar roles can feel lost⁽¹³⁶⁾. Restoring a sense of routine can help to recover a sense of self^(173, 182). Identities are often negotiated through relationships with other people⁽¹⁴⁶⁾, in particular between couples. Gender roles are implicated here – traditional (“hegemonic”) masculine roles can be affected where sexuality is temporarily or permanently affected by treatment^(150, 183), and domestic roles such as husband and father can be difficult to maintain⁽¹⁶⁶⁾. Recent literature is beginning to move beyond this uncomplicated view of masculinity, describing a greater flexibility in male values among patients – for example, a willingness to disclose difficulties and seek emotional support^(136, 171). This allows more possibilities for adaptation to the symptoms brought about by treatment.

The literature notes that the “survivor” label is not always helpful in crises surrounding identity, supporting the discussion in Chapter 1, section 1.3 – it can work against the maintenance of aspects of identity unrelated to cancer^(86, 136, 137). There is a need to retain a sense of self during treatment by decentralising the illness^(136, 160) – this can emerge from thinking about experiences separate to the cancer that have contributed to an individual’s sense of who they are as a person^(136, 164), or by conceptualising cancer as something outside of the self rather than as incorporated within it⁽¹⁶⁵⁾.

2.2.2.3 Biography

As identity is renegotiated, a legitimate place must be found for cancer in a person’s life story. Lagerdahl, Moynihan and Stollery⁽¹⁵³⁾ frame the changes brought by the disease as a temporary loss of authorship over life. The task of recovery is to rebuild a sense of authorship in the face of uncertainty. Kaiser⁽⁸⁶⁾ refers to this regaining of control as “retooling” – making new meanings from experience which help to structure and shape ongoing life. Ching, Martinson and Wong⁽¹⁶⁰⁾ also describe the need to exert control, and to recover the ability to predict or imagine a future. A key tool for

reframing meaning is narrative. We construct stories at a cultural and individual level to weave our experiences together into a unified whole – a biography which extends into our likely future.

In the literature exploring patient perceptions of cancer, narratives of disruption and difficulty are more prevalent than narratives of recovery. Cayless *et al*⁽¹⁶⁵⁾, McCann *et al*⁽¹⁸¹⁾, Lilliehorn *et al*⁽¹⁷²⁾ and Rasmussen and Elverdam⁽¹⁷³⁾ draw on Bury's conception of chronic illness as biographical disruption^(116, 184) to explain aspects of cancer patient narratives. Discontinuities are described in patients' relationships, identities, and visions of the future⁽¹⁶⁵⁾, in their bodies and functionality⁽¹⁸¹⁾, and in the structure of their day-to-day lives – in particular for those who are still working and have to take a break⁽¹⁷³⁾. Lilliehorn *et al*⁽¹⁷²⁾ construe biographical disruption as a catalyst for the existential concerns described in section 2.2.2.1.

Disruption encapsulates the idea of living with uncertainty – not only about cancer recurrence, but about how to re-engage with life when it feels chaotic or lacking in meaning. This state is also conceptualised as liminality⁽¹⁶⁵⁾ or limbo⁽¹⁷⁵⁾. Liminality has previously been explored in relation to cancer patients⁽¹⁸⁵⁾, characterising the permanence of the “cancer patient” label regardless of a lack of evidence of disease. This can bring feelings of isolation from others, an increased sense of powerlessness, and an awareness of the limits that time can impose on life. McCaughan *et al*'s⁽¹⁷¹⁾ colorectal patients summarise liminality as an existence that is lived “halfway between two worlds”^(p66) – when treatment is complete they are no longer cancer patients, but they do not see themselves as “normal” in the way that they were before. McCaughan *et al* (among others) conceptualise this as the “new normal”.

The sense of liminality can differ dependent on cancer types, prognosis, and the experience of treatment. Strategies for resolving the anxiety of liminality are reported among Cayless *et al*'s prostate cancer patients⁽¹⁶⁵⁾, who minimise the disease by focusing on its relatively common occurrence and the longevity of other sufferers. Ohlsson-Nevo *et al*⁽¹⁴⁸⁾ describe how colorectal cancer patients can be left in a state of liminality after treatment has been completed – a smooth recovery can leave patients feeling uncertain that the cancer was real, leading to a struggle to conceptualise ways of adapting, psychologically, to their experience.

Biographical meaning-making is also represented in sociological illness narratives, which describe a range of responses to cancer. Frank⁽⁹⁹⁾ conceptualised three narratives of restitution (returning to health), chaos (never ending illness) or quest (positive transformation through illness), drawing on experiences across the cancer trajectory. The literature included in this review considers a narrower population – the majority of study participants were in the first year beyond treatment for cancers with median survival rates of five years or more. Three papers consider patients' experiences in the light of Frank's narratives – two explore breast cancer^(86, 174) and one oral and colorectal cancers in older men⁽¹⁶⁴⁾. These papers find evidence of all of Frank's narratives among patients with early and late stage diagnoses in the first few months beyond treatment.

Frank's⁽⁹⁹⁾ restitution narrative follows the medical model of diagnosis, treatment and cure, and suggests an imperative to return to "normal". Kaiser⁽⁸⁶⁾ identifies the restitution narrative with survivorship, but advocates an acknowledgement of the contingencies that affect the stories patients choose to tell – reflecting Frank's description of his narrative categories as permeable rather than exclusive. Martin *et al*⁽¹⁶⁴⁾ draw attention to the concept of reconstruction rather than restitution, where normality is not regained⁽¹⁸⁶⁾, and to the concept of rehabilitation, also explored by Høybye and Tjørnhøj-Thomsen⁽¹⁶²⁾. Rehabilitation encompasses practical health interventions, but as a theoretical concept, the term has also been applied to the renegotiation of sense of self which occurs in the period after cancer treatment⁽¹⁶²⁾.

2.2.2.4 Defining the disease: cured or chronic?

Charmaz describes how the experience of illness provokes a need to define it – Charmaz's male patients characterised chronic illness as an enemy, an ally, an intrusion or an opportunity⁽¹¹⁷⁾. Illness also awakened their awareness of mortality and a need to preserve their identity during a period of loss and change. Foster and Fenlon⁽¹⁴³⁾ echo the parallels between the cancer experience and theories of chronic illness, citing the enduring nature of the changes brought about by treatment – in particular the impossibility of subsequently returning to "normal" in the face of social stigma and persistent physical effects. The literature in this review includes cancers treated with

curative intent – the meaning-making of the patients in these studies does not exclude the concept of cancer as an acute episode, and illustrates a tension between the hope for a cure and definitions of cancer as a chronic disease.

Cancers with high five-year survival rates that are treated with intent to cure are open to different definitions than cancers with a poorer prognosis. Cancer types that are highly treatable (such as early cancers of the testicles or larynx) are sometimes labelled “good” cancers by health care professionals^(136, 152). Good prognoses may allow more positive adjustment patterns, allowing people to hold on to positive illness beliefs, minimise the significance of the disease, and see their disease as acute rather than potentially chronic⁽¹⁶⁵⁾. For Matheson *et al*’s testicular cancer patients⁽¹³⁶⁾, these strategies enabled an active approach to overcoming the threat of cancer based on the ability to relinquish fears about recurrence, and the consequent preservation of a sense of self. In contrast, where cancer creates a permanent feeling of uncertainty about being “cured”⁽⁸⁶⁾ – where fear of recurrence makes the disease omnipresent⁽¹⁴⁸⁾ – patients can see disease prevention as out of their control, and this can impact on their motivation for healthy behaviours^(148, 175).

The conceptualisation of cancer as an acute episode is not restricted to the highly treatable “good” cancers described above. For example, colorectal cancer patients can set recovery goals that are inappropriately short term, linked to their desire to see their illness as acute⁽¹⁴²⁾. McCaughan *et al*’s colorectal cancer study⁽¹⁷¹⁾ demonstrates the role that gender might play in this – their male patients were more likely than their female patients to minimise the effects of cancer as a strategy for adaptation. This period of minimisation can be time-limited, depending on the severity of the cancer and its therapy – the chronicity of the changes brought about by the disease can become evident during treatment⁽¹⁵²⁾ or much later⁽¹⁴³⁾. In Vaartio, Kivineimi and Suominen’s exploration of men’s experiences across a range of cancers⁽¹⁶⁶⁾, participants did not see the disease as chronic. Instead they displayed a strong desire to return to normality after treatment, and a lack of acknowledgement of the more enduring nature of changes brought about by treatment regimes.

Framing cancer in a positive light at the point of diagnosis can raise expectations unhelpfully^(124, 181). Ridgway *et al*’s⁽¹⁵²⁾ study of the effects of the “good” cancer label

on men and women with cancer of the larynx/thyroid points out how patients' high expectations dissolved as treatment progressed, where therapy included a period of enforced isolation in hospital and resulted in visible physical disfiguration. When physical changes can be hidden underneath clothes, a tension can arise at the end of treatment between what is outwardly "normal" and the patient's experience of change. This can be reinforced when close friends and relatives view the illness as an acute episode that is over, and support dwindles^(124, 181). The concept of cancer as an acute episode fails to recognise the fundamental change or "transition"⁽¹²⁹⁾ that occurs when cancer becomes a permanent feature of a person's history.

2.2.2.5 Defining the disease: the role of other people

The construction of definitions of cancer experience is a collaborative effort between the patient and the people who surround them^(124, 149, 181). When a cancer diagnosis is disclosed, other people offer their own definitions of the experience⁽¹³⁶⁾, and of how to manage it⁽¹⁶⁸⁾. Illingworth *et al*^(144, p25) describe the "joint ownership" of cancer between partnership dyads, and joint definitions, such as the decision that the patient will not become a "victim" of the disease^(p26). Definitions offered by close family members are not always helpful – for example, in Coyne and Borbasi's study⁽¹³⁸⁾ a participant's mother sees her daughter's disease as a death sentence. People can also derive meanings about their cancer from family memories – for example, from defining another family member's response to a cancer diagnosis as strong willed, and wishing to emulate this⁽¹⁶⁰⁾.

The literature suggests that the most usable definitions of cancer are those offered by other patients who have shared the same experience: contact with other patients can increase a sense of control^(137, 154), and making comparisons with other patients' experiences as a way of calibrating or minimising your own experience can be a helpful exercise^(124, 136, 154, 165, 168). The research acknowledges that peer support from other patients is not a universally positive resource, however – efforts to meet others in the same situation can cause additional stress when visits to hospital are no longer the norm⁽¹⁷⁶⁾, and some patients see peer support in a negative light as a way of continuing to dwell on cancer when treatment has finished⁽¹³⁸⁾.

2.3 Key topics in the literature about patients' experiences

The literature is structured by cancer type or key topic, and guided by the theoretical approaches described above. Key topics include communication and the provision of information (mainly focused on contact with professionals at point of diagnosis and during treatment), spirituality, cultural differences, sexuality and reproductive issues, and returning to work. These are summarised below. The data described in the literature largely focus on experiences that are common across more than one cancer type, as do the theoretical frameworks above. Where cancer type is salient to the patients' experiences (pertinent in the area of sexuality and reproduction, and in the return to work), its significance is described.

2.3.1 Information and communication

The literature considering patients' communication and information needs in the first year of treatment is sparse, but does contain common themes centred around how patients perceive their experiences of professional communications during treatment and recovery. Communication by health care providers at the point of diagnosis and treatment is made complex by the wide variation in information needs and preferences between one patient and another^(187, 188). The personal characteristics and social demographic of patients can impact the benefits of information provision⁽¹⁸⁷⁾ – some patients wish to be armed with more information than they are offered, others would rather not know details, have low health literacy, or prefer to find out information about their situation in stages as treatment progresses. Studies demonstrate that the shock of diagnosis often compromises a patient's ability to absorb the information that they are given prior to treatment⁽¹⁸²⁾.

Diagnosis is a moment when expectations about the future can be overturned – the emotional response is described by most patients as too intense to allow them to take relevant information on board⁽¹⁸⁸⁾. Retrospectively, patients can feel that they were given too much information at a time when it was difficult to take in, or that the full details of treatment or surgery might have made them refuse treatment. Høybye and Tjørnhøj-Thomsen⁽¹⁶²⁾ show how variable patients' experiences of communication are, and how interactions with health care providers can form the core of someone's

experience of their disease, treatment and ongoing effects. Patients may rely on health care professionals to provide a positive take on their situation, regardless of the details of their diagnosis, as a way of facilitating coping with treatment⁽¹⁸⁸⁾.

During treatment, the way patients feel in response to interactions with health professionals shapes the way that they tell their illness stories, and can have implications for adaptation to life after cancer⁽¹⁶²⁾. If interactions recognise the patient's sense of agency and individuality, health care providers are perceived as attentive and living up to expectations of good caregiving, and patients feel a sense of control over their own recovery. This requires a level of skill on the part of the professional, including the ability to convey empathy. Where care is fragmented (shared across different departments or institutions), patients can feel unrecognised as individuals, and more like a number in a medical system⁽¹⁸⁸⁾. This is compounded when medical interactions, including treatment routines, are administered by professionals in a way which fails to distinguish one individual from another, creating a feeling of objectification or dehumanisation on the part of the patient. Reducing a patient's sense of agency can make it more difficult for them to make decisions about treatment or reframe a sense of self in the face of change⁽¹⁶²⁾.

There is a consensus in the literature that the year beyond treatment is a period in which information is increasingly required, but less readily available. Patients move beyond the shock of diagnosis and the immediate effects of surgery, chemotherapy or radiotherapy, and begin to live with longer-term physical consequences of treatment that they might not have anticipated^(150, 152). It is a period in which optimistic expectations about the speed of recovery might not be met⁽¹⁸⁷⁾. Adaptation is required, and information given at the beginning of treatment may no longer be adequate. At the end of treatment, the day-to-day management of ongoing physical and psychological effects continues without regular specialist help. Sparse information about what to expect during recovery can leave people feeling a lack of closure as treatment finishes⁽¹⁶⁹⁾.

2.3.2 Spirituality

The literature on adaptation in the year after cancer interprets spirituality as a belief in God, with the exception of studies from China^(151, 160) focusing on its wider connotations encompassing the development of the human spirit or soul. Some research studies conflate spirituality with culture, as it is a key differentiating feature between ethnic groups. The unifying feature of studies examining spirituality in people with cancer is the connection they make between spiritual beliefs and the construction of meaning in the face of illness. Considerations of meaning-making centre around the issues of control and companionship, and consider how religious beliefs can provide strategies for coping.

Beliefs within the traditions of Confucianism, Buddhism and Taoism place an emphasis on fate and external control, and this influences views about the cause of illness, which is seen as an expression of disharmony^(151, 163). Survival through serious illness is seen as down to fate, rather than as within an individual's control, although there is an obligation to attempt to regain harmony or balance through diet and exercise. Theist religions provide narratives which relinquish control to God during treatment and immediate recovery⁽¹⁴⁵⁾, seeing illness as God's will^(145, 154, 177) – leading to greater acceptance, an ability to ask God for help, and a consequential lessening of fear and distress. In this way, religious beliefs can offer comfort in the face of existential angst⁽¹⁶⁷⁾. Control can be actively given up to God, but is also passively surrendered where religious norms prescribe behaviour – for example, cancer can bring a moral obligation to be thankful to God, implying that the experience is a gift containing hidden benefits⁽¹⁴⁵⁾, or prescribe hopefulness as a way of resisting death⁽¹⁵⁴⁾.

Faith brings companionship in real or virtual ways through the existence of a church community and the act of prayer⁽¹⁷⁷⁾. An increase in attendance and prayer during and after treatment can bring a sense of spiritual and social support^(147, 154). People with cancer who are not able to attend services can be remembered in prayers and reassured by this continuing connection. Bible stories can provide role models for facing adversity that can be drawn on to create helpful psychological strategies, such as beliefs about inner strength⁽¹⁴⁵⁾. Acceptance by family members can also be facilitated by the interpretation of their caregiving role as a calling⁽¹⁴⁵⁾.

Religion and spirituality rarely appear in literature considering Western cultural perspectives – only two Western-focused papers directly considered spirituality^(167, 177), and interpret it in a positive light as a resource for social support and existential reassurance. The majority of the literature on spirituality in the year after cancer treatment details the positive aspects of faith and fails to consider obligations or prescriptions for behaviour that might emerge from religious beliefs. A consciousness of the bias towards positivity in the cancer literature as a whole suggests that this might present a partial picture of their significance.

2.3.3 Cultural differences

Six of the fifty-one papers reviewed took a deliberate focus on non-Western cultures: two considered African American women^(145, 147), three Chinese women^(151, 160, 163) and one Iranian women⁽¹⁵⁴⁾. All six papers were breast cancer studies including patient perspectives (all female); three included caregivers in their samples^(145, 147, 151). It was generally agreed in the background to these studies that people who have migrated to other countries can experience language difficulties which hamper communication with health care professionals, and often have lower social status and poorer access to good care as a result.

The findings of the papers focus on psychological and social strategies for coping. When read against papers dominated by a Western perspective, they highlight differences in adaptation to life after cancer treatment based on cultural norms. These are often evident in the more prominent role played by spirituality, but spirituality is often conflated with ethnicity in descriptions of coping with cancer^(145, 147, 151, 154, 163) and is discussed separately in the section above. Further differences are evidenced in attitudes towards family, interpersonal relationships and body image, and in the level of significance accorded to personal control in the face of illness. These are discussed below.

The close interdependence of family members in Chinese society provides a system of support that is immediate and unquestioned at the point of diagnosis^(151, 160, 163). In Chinese culture, the patient's responsibility is to the family rather than the self⁽¹⁶³⁾ – hiding strong emotions, believing in survival and maintaining "face" by preserving the

family's outward appearance to others forms part of their role as a person with cancer⁽¹⁵¹⁾. Cancer recovery is an activity shared by the family unit: the rebalancing of family roles, and changing health behaviours for the better (such as formulating a better diet) are seen as family tasks rather than the individual responsibility of the patient⁽¹⁵¹⁾.

Within marital relationships, the practical activities attached to gender roles (for example, cooking and caretaking being seen as a woman's role) are less entrenched in Western accounts of social support – however, in the literature from all cultures, husbands of breast cancer patients are represented as providing good support, adapting any assumptions about gender-appropriate domestic activities in order to provide care^(147, 149, 151, 154). A marked difference in the literature from China is the lack of concern about how the loss of a breast will affect appearance and sexuality – health is seen as a greater priority⁽¹⁶³⁾.

The strong significance of interpersonal relations and a willingness to involve social networks is also evidenced in studies of African American women^(145, 147). A high level of social support combined with strong spiritual traditions in Chinese and African American cultures allows an acceptance of illness – a giving up of control, which contrasts with the discomfort with dependency described in some Western experiences^(143, 153, 165). Fatalism is connected with this giving up of control, and is a prevalent theme in Chinese accounts of cancer, but is not common to all Chinese patients^(151, 160, 163). Pressure to display positivity is experienced by Chinese patients – balance and harmony are valued above emotional expression. In Western culture, positivity has become an imperative of the “survivorship” label; in China the perception of a direct causal link between positivity and health/a lack of cancer recurrence is a stronger motivation to avoid negative thinking⁽¹⁵¹⁾.

2.3.4 Sexuality, intimacy and reproductive issues

Treatment for gynaecological cancers or for prostate and testicular cancer can compromise fertility and/or cause sexual difficulties. From the patient perspective, there is often a delay in consideration of these issues until several months after

treatment⁽¹⁸²⁾, and the loss of body parts such as a breast or a testicle can have symbolic ramifications in terms of gender identities and intimate relationships⁽¹⁵⁴⁾. Where there is a lack of adequate information, or communication with professionals is difficult at the point of treatment, expectations about sexual function after treatment can be unduly positive⁽¹⁵⁰⁾, and a sense of disenfranchisement can arise in the months that follow as the work required to adapt or recover becomes clear.

The cancer literature as a whole demonstrates a paucity of effective strategies for communication about sexuality and intimacy on the part of health care providers^(139, 183, 189). Discussions about intimacy are often based on stereotypical assumptions about patients' sexuality based on their demographic characteristics, and can be hampered by embarrassment and awkwardness. For many patients, survival may be the first imperative at the point of treatment. The shock of diagnosis shifts the focus away from the potential effects of surgery, radiotherapy, chemotherapy or hormone therapy on sexual life, and it is only in the six to twelve months following treatment that the magnitude of the effects begins to be felt^(139, 182, 189). Information given before treatment is seen as potentially more appropriate in its timing than broaching the subject shortly after treatment, when dealing with the physical sequelae can make it difficult to absorb new information^(139, 183). Some patients assume that infertility is an unavoidable consequence of treatment – others suggest that fertility concerns are low at the point of treatment, preventing effective decision-making and resulting in a sense, subsequently, that fertility has been stolen away without their knowledge⁽¹⁸⁹⁾.

Fertility concerns are also connected with the broader issue of the actual or symbolic loss of the ability to perform gendered roles – through a loss of sexual function or of body parts involved in reproduction⁽¹³⁹⁾. While this is more prevalent among younger cancer patients who have yet to start a family, it also causes concern among patients who already have children, in connection with changes in body image and assumed family roles. Perceptions of femininity or masculinity can be changed by the effects of treatment on appearance and sexual function, and this in turn affects behaviour in intimate relationships⁽¹⁵⁰⁾. Sexual function can be seen as an expected part of the marital (or partnering) role, and the resumption of a sexual relationship may be an

imperative above and beyond the patient's own intimate needs⁽¹³⁹⁾. Not all patients suffer from long term distress over the changes brought by cancer treatment – for example, women with completed families who have been treated for cervical and endometrial cancer may feel that they benefit from no longer having to deal with menstruation when treatment causes menopausal symptoms⁽¹³⁹⁾.

2.3.5 Returning to work

The majority of the literature examining the return to working life after cancer treatment focuses on the individual coping strategies that evolve during the first weeks of employment, and on the functional limitations that might make this difficult. The twelve months following cancer treatment usually include the transition period back into work, and the literature focuses on the shifts in experience that begin at the end of treatment. Two main issues arise – a consideration of the functional limitations imposed by treatment and how these may affect task capability at work, and the social aspects of returning to the workplace, drawing on public discourses about cancer and the expectations that these create among employers and colleagues.

Sandberg, Strom and Arcury⁽¹⁹⁰⁾ consider functional issues that may be unresolvable in the short term, such as fatigue and lymphoedema (swelling in the arms following breast cancer surgery). They describe strategies breast cancer patients have used to address these limitations – for example, requesting extra help, adapting tasks and reducing hours – and point out the difference between formal and informal strategies (informal strategies being those practiced without explicit consent from an employer). Leading issues experienced in connection with the return to work are how it operates as a distraction from cancer, how stigma can colour the return to work (in particular for men), and how the loss of work impacts on the structure of day-to-day life.

The experience of social support during diagnosis and treatment – when extra time is often spent with family members and supportive friends – leads to a recognition of the value of family and social networks. In the period following treatment, patients often make a decision to make changes to working patterns in order to maintain these networks. For some, resuming work can compromise the motivation or ability to put these plans into practice⁽¹⁴⁰⁾. The return to work can be seen as a distraction from

cancer, as a doorway back into normative experience – a recovery of routine which retrieves the person from their cancer experience and returns them to their previous life⁽¹⁴⁰⁾. Expectations of normality are disrupted when resuming work highlights a mismatch between previous and current functional capabilities – when fatigue or mobility issues prevent the person from the complete recovery of their original work role. Absence from work for cancer treatment, even where this is a relatively short term phenomenon lasting a few weeks, can also lead to a sense of a loss of skills on the return to work^(140, 173).

Social issues surrounding the return to work also include stigma and embarrassment in front of work colleagues as a result of functional issues, and the effect of periods of absence on other people's perceptions of the returning colleague's fitness for their job. The relationship between work and identity relies not only on individual perceptions of the self, but on how a person feels that they are perceived by others. Stigma takes many forms. It can be dependent upon the type of cancer – for example, men recovering from prostate cancer can be conscious of the disease's connection with a perceived loss of sexual prowess⁽¹⁶¹⁾, which may bring embarrassment. Lay beliefs about the causes of cancer – for example, linking gynaecological cancers with sexual promiscuity – may cause anxious anticipation of unspoken censure from colleagues⁽¹⁴⁰⁾. This can lead to a reluctance to disclose the reasons for absence from work, and a lack of understanding among work colleagues of the potential physical complications of treatment (for example, the need to visit the toilet more frequently – an effect of prostate or colorectal cancer treatment).

Grunfeld *et al*⁽¹⁶¹⁾ report that men treated for prostate cancer feel a pressure to display traditional male characteristics of strength and stoicism, and as a result are less likely to disclose the details of their disease – although disclosure is helpful, when it occurs. A comfortable return to work can be compromised by the person's perception that their absence has become more salient to work colleagues than their previous presence at work. If changes to work practices must be made to accommodate the late effects of treatment, this can lead to feelings of incompetency in front of colleagues.

Broader issues connected to social norms affect those who take an enforced absence from work. Rasmussen and Elverdam⁽¹⁷³⁾ draw on aspects of the Protestant work ethic

explored by philosopher Max Weber to characterise the experience of the return to work after cancer treatment. Weber *et al*⁽¹⁹¹⁾ describe how the Western cultural focus on the individual leads to a discourse of self-reliance – an expectation that work is a natural and necessary part of human experience that helps to structure everyday life (see the discussion of freedom under section 2.2.2.1). To Weber, social relations at work are as salient to the individual as family relations are at home.

Work is outside of the self – a framework for living that the individual can subscribe to. Cancer interrupts an individual's ability to tap into this structure, and a way of re-engaging with everyday life needs to be negotiated or relearned – one of Rasmussen and Elverdam's⁽¹⁷³⁾ participants with cancer states: "It is as if the dynamics come from the outside, you have to create a counterpart"^(p1236). Everyday activities establish what is "normal", and for those who have a job they value, work generates and organises everyday life⁽¹⁷²⁾. When work cannot resume in the same way as before treatment, everyday life becomes less recognisable⁽¹⁷⁵⁾ and less satisfying⁽¹⁷²⁾. For some patients, the interruption of normality that came with cancer treatment provoked a change of perspective, and a reappraisal of the personal value of their employment⁽¹⁷²⁾.

2.4 Exploring the limitations of the literature

From the information supplied about methodologies in the papers included in this review, a picture emerges of potential limitations connected with sampling, methods and theoretical approaches. These are explored below, followed by some suggestions about which areas of the experience of life after potentially curative cancer treatment might benefit from further research.

2.4.1 Sampling participants

One key characteristic of the qualitative studies in this review is the recruitment of homogeneous samples of participants. The experiences of white Western participants predominates in all papers with the exception of six studies looking at the breast cancer experiences of Iranian women⁽¹⁵⁴⁾, African American women^(145, 147), and Chinese women in China^(151, 160) and as immigrants in Australia⁽¹⁶³⁾. There is a distinct bias towards the study of breast cancer (see Table 2, overleaf), towards the inclusion

of female participants, and towards the experiences of participants of retirement age, most of whom reported themselves to be financially comfortable. Papers considering the return to work included mainly white-collar workers, and little attention is paid to social deprivation, except to specify its association with minority ethnic groups. Purposive analysis of the mediating role of gender⁽¹⁷¹⁾ and age^(168, 170) was restricted to three papers, but did appear in aspects of the findings in other papers under discussions of male cancer narratives⁽¹⁶⁴⁾ and gender roles^(139, 154), and was implicit in discussions of cancer types specific to men or women (there were no studies exploring men’s experiences of breast cancer).

Breast	21
Colorectal	6
Prostate	4
Head and neck	4
Gynaecological	3
Testicular	2
Various: colorectal/head and neck/oesophageal	1
Various (5 or more cancer types)	10

Table 2 *Number of studies per cancer type (total number of studies: fifty-one).*

Finding papers specifically focused on the first year of recovery from primary cancer treatment relied on reading abstracts and information on sampling and methods – few papers specified a timescale in their title or key words. The majority of papers retrieved in the initial search included participants recruited from very broad “survivorship” windows – for example, living beyond cancer for between one and fourteen years in a single study^(192, 193), or at various unspecified stages of disease^(194, 195). Many deliberately excluded people living with cancer for less than one or two years⁽¹⁹⁶⁻¹⁹⁸⁾, or people living with cancers that were not judged to be life threatening⁽¹⁹⁹⁾.

Lagerdahl, Moynihan and Stollery⁽¹⁵³⁾ suggest that we narrow our timepoints when we investigate the post-treatment phase. The potential difficulties of this are implied by the approach of longitudinal studies in this review, which presented analytic findings that did not reflect the timepoints of data collection^(133, 140, 161, 181, 188). There are questions to answer in terms of whether it is possible in practical terms to recruit for interview studies within tightly specified temporal windows, whether patients' retrospective narratives of diagnosis and treatment can be separated from narratives of adaptation or recovery, and whether "recovery" is a suitable word in relation to a disease we have begun to regard as chronic.

2.4.2 Methodological issues

Considering research methods, McSorley *et al*⁽¹³³⁾ point out the possibility of a bias towards positivity, acceptance and stoicism in interview studies. They have a sound basis for this statement: their mixed methods examination of coping in men with prostate cancer identified strategies involving dependence on alcohol or drugs and tendencies to self-blame in their quantitative survey that did not arise in their qualitative interviews. Recruitment for interview or focus group studies of the cancer experience relies on the participation of people who are willing to volunteer their stories for examination – arguably, people experiencing difficulties with coping are less likely to wish to volunteer their time, to dwell on their experience in detail, or to share their difficulties in the face of potentially negative judgements about their coping abilities.

The key topics outlined in section 2.3, above, demonstrate the focus of the research studies on embodied experience, clinical communication, and how the frameworks provided by work, culture and spirituality affect coping and meaning-making. All papers described social processes facilitating or inhibiting adjustment to life after treatment, but explicit descriptions of key processes in positive adaptation were restricted to three studies^(136, 149, 160): elements of positive adaptation included the construction of meaning from the experience^(136, 149, 160), acceptance^(136, 160), and the effective use of social support^(136, 149). Striving towards normality and the preservation of self are described as processes that occur alongside accepting – and

minimising – the psychological and physical changes brought by treatment^(136, 160). Recommendations for positive adaptation strategies are not restricted to papers presenting models: Beatty *et al*'s study of women with breast cancer⁽¹³⁷⁾ draws out, within its themes, a range of suggestions from patients for addressing difficulties. Some of Beatty *et al*'s recommendations are based on the concrete use of everyday resources – for example, closure ceremonies to donate wigs or scarves after chemotherapy is complete.

2.4.3 The use of theory

There is a lack of explicit recognition of existing theoretical thinking in a minority of the papers considered in this review. A small subsection of studies are well grounded in theory – Lagerdahl, Moynihan and Stollery's exploration of existential experiences in people curatively treated for cancer being a good example⁽¹⁵³⁾. Many studies examine concepts that have been explored in other work, but fail to incorporate a broad range of relevant theoretical thinking. For example, Feher and Maly's study⁽¹⁷⁷⁾ links religious beliefs with meaning making, but does not mention existential concerns, missing an opportunity to explore how religious beliefs address existential anxieties.

Crossover between theoretical concepts is evident – for example, between identity as a stand-alone concept (sense of self), as a catalyst for meaning-making or biographical disruption (when discontinuities in identity are evident), and as a fundamental building block for the confidence that helps people to set goals and move forwards. This crossover sensitises and deepens understandings of what it is like to experience cancer. To expand our thinking beyond what has already been sketched out in a way that acknowledges the existing picture, grounding further studies in existing theory is vital.

2.4.4 What might be missing?

Martin *et al*⁽¹⁶⁴⁾ argue that the diversity of responses to cancer (both within and between cultures) are obscured by grand narratives such as the survivorship metaphor – care needs to be patient-centred, and as such, much recognise the potential nuances of the patient experience, rather than creating generalised metaphors that suggest or

prescribe particular types of behaviour. Matheson *et al*⁽¹³⁶⁾ view generalisations about cancer as potentially leading to misconceptions about the experience. Foster and Fenlon⁽¹⁴³⁾ point out the opposite danger – of creating prescriptions for behaviour based on the individual experiences of patients described in sociological research that may not translate to other individuals. This reflects a common criticism of qualitative research as anecdotal, based on the presentation of idiosyncratic comments from participants as overarching themes^(200, 201). Rigorous qualitative research can guard against this accusation by indicating, in the writing up of findings, the breadth of occurrence of particular thematic strands across a series of interviews⁽²⁰²⁾.

Research has open to it a number of routes to investigate patient experience – for example, to consult the individual patient, to gather small groups of patients together to share and discuss experiences, or to examine patient experience on a much larger scale using statistics, basing the grouping of samples on concepts defined by broad terms such as “survivor”. This thesis subscribes to the view of Martin *et al*⁽¹⁶⁴⁾ that individual patient narratives can be usefully examined with a focus on unearthing ranges of possibility in responding to cancer, for example by focusing on samples with similar or uniting characteristics (Martin *et al*'s paper examines the experiences of war veterans from six to nineteen months beyond cancer diagnosis). The patients who will be eligible for the self management pathway in follow-up care for cancer comprise one such group.

Palmer *et al*⁽¹⁴²⁾ advocate the chronic care model as an appropriate means of goal setting during follow-up, but acknowledge that this approach currently excludes post-treatment cancer survivors who are not on a chronic trajectory. We cannot rely solely on borrowed ideas from models of chronic illness – cancer has a long and unique history of its own⁽¹⁵⁹⁾, and we must take into account all of the associations that the word “cancer” now entails by continuing to talk to people who experience the disease as treatments and outcomes change.

2.4.4.1 Summarising the key issues

In the literature reviewed above, coping with an episode of cancer is dependent upon people's dispositions, their internal cognitive strategies and their interactions with

significant others. Meaning-making can make the difference between positive or negative adaptation to cancer diagnosis, and is seen as emergent from interactions with health care professionals and from previous experiences within social structures (social networks and places of work).

The tension between conceptions of cancer as acute and chronic is not lost on people with cancer, and the literature is beginning to consider how they might wish to hold on to interpretations of cancer as an acute episode alongside their fears about chronicity. Inhabiting the liminal space within which discontinuities of identity and biography play out is uncomfortable, and sociologists suggest a range of narratives which can lend structure to this experience. For patients treated with curative intent, there is a suggestion that we can add further nuance to the positive frameworks for adaptation offered by Frank – those of restitution and quest⁽⁹⁹⁾ – for example, through concepts such as reconstruction⁽¹⁶⁴⁾ or rehabilitation⁽¹⁶²⁾.

Reviewing the literature in terms of its key topics, there has been considerable focus on how the experience of cancer is characterised by the following: communications with health care professionals, changed experiences of embodiment, and the impact of spiritual beliefs and cultural norms. Communication issues centre around the time of diagnosis – patients comment on the absence of clinical communication and information in the year beyond treatment. Embodiment issues impact on sexuality, fertility, identity formation and the resumption of social and working life. When treatment is over, people are often alone in managing its negative effects (for example, the disruption of life plans, changes in intimate relationships and the minimisation of stigma). Spiritual and cultural issues are well investigated in descriptions of coping in African American and Chinese breast cancer patients – but the role of social norms in Western cultures is less well explored, with the exception of the “survivor” label and the prescriptions for behaviour that this implies.

If we are to ask patients who have been curatively treated to be managers of their own welfare after treatment – if we are going to go beyond measuring needs and suggest ways of addressing them – what can we advise in terms of how this can be done? If clinical follow-up is largely withdrawn at the end of treatment, what resources for adaptation remain? The literature suggests the following: good intrapersonal skills

(abilities at coping, or cognitive adaptation, and the ability to make meaning), and effective interpersonal interactions (in the form of the social support of family and friends). The literature also suggests that each of these resources is dependent, to some extent, on the other – coping and meaning-making on interactions with other people, and social support on the ability to display good coping skills. The focus of qualitative research on the person and the social processes in their close networks has so far missed one key ingredient: a consideration of the social and material environments where adaptation is lived out, and how these dovetail with the individual and social resources mapped out in the existing literature.

Adaptation happens in the home and in the local community. While quantitative research has pointed out associations between levels of social and material resources and longevity after cancer treatment, the contextual issues surrounding the use of these resources has been little explored using qualitative methods. Everyday resources include the social interactions and material objects available in the home and the local community. If the self care agenda is to engage with the concerns and challenges of day-to-day life, we need to examine what everyday resources people might already possess to facilitate adaptation, and how these shape and are shaped by the social worlds around them.

2.5 Chapter summary

This chapter has described the strategies used to search for existing qualitative literature exploring experiences of adaptation in the year after treatment for a primary cancer. The search retrieved fifty-one academic papers focused on patient experiences during all or part of the twelve months beyond treatment. The review aimed to examine the use of theoretical frameworks, consider the key topics focused on by qualitative research to date, and explore the potential limitations of the literature. Two overarching theoretical concepts were identified as key ways of interpreting patients' experiences: coping and cognition, and meaning-making. The utility of concepts connected with individual and relational coping were explored, and the application and overlap of further theoretical ideas related to meaning-making – existentialism, identity and biography – were examined in relation to patients' experiences. Five key

topics were examined in the existing research: information and communication; spirituality; cultural differences; sexuality, intimacy and reproductive issues; and the return to work. In the context of the self care agenda discussed in Chapter 1, there is a lack of consideration of how everyday social and material resources in the home and local community might be used to facilitate adaptation in the year following cancer treatment with curative intent. This is the focus of this PhD study.

2.6 Research questions

The research questions for this study ask:

- What are people's key concerns when they complete treatment for a primary cancer with curative intent?
- How might meaning-making shape people's experiences in the year beyond treatment?
- How do people make use of everyday resources to adapt to life in the year beyond treatment?
- How might demographic characteristics mediate experiences of adaptation and recovery?

Chapter 3: Primary breast, colorectal and prostate cancer – therapies and treatment effects

They give you a very thorough description of how things are normally...what the treatments are, and why you have this treatment or that treatment...

It's a great thick wodge...it reads like the kind of thing you get with pills, you know – every conceivable side effect, with the addition that is a further flowering of alternative treatments for each one of these individually...so you glance at this thing and think: I've got to throw it away.

Stephen (84/PC), Interview 1

3.1 Introduction

This study engaged participants treated for one of the three most common cancers with the best survival rates: breast, colorectal and prostate cancer. This chapter focuses on the physical aspects of cancer therapies, describing the features of early-stage breast, colorectal and prostate cancer, outlining approaches to potentially curative treatment as they were practiced in 2014 and 2015 when recruitment took place, and considering the longer term effects of treatment. The treatment protocols described below are based on information from Cancer Research UK, the National Institute for Health and Care Excellence and the National Collaborating Centre for Cancer^(65, 66, 203-209); statistics are referenced to specific documents where appropriate. This is not intended to be an exhaustive or authoritative description of cancer treatments, but is provided solely to set participants' experiences in context.

3.2 What is cancer?

The process of cell renewal in the human body sometimes functions abnormally. When cells mutate and grow in an uncontrolled way, the body can develop a tumour – a mass of cells with no physiological function. Some tumours are benign – they remain self-contained and do not spread from their original site. Others erode the tissue surrounding them and spread to other sites – these are malignant tumours, or cancer.

3.3 The staging and grading of cancer

Doctors classify malignant tumours by the site of their origin and the type of cells they contain. The stage of a cancer refers to its size and spread, and is classified using the acronym TNM: “T” indicating the size of the tumour, “N” how far the cancer has spread into the lymph nodes, and “M” referring to its metastasis – its spread into other areas of the body. The grading of a cancer indicates how similar the cancer cells look to unaffected cells nearby. In low grade cancers, cells and cell patterns look relatively normal and cancer grows slowly; in high grade cancers, cell shapes and patterns look markedly different and cancer grows faster. The grading of prostate cancer has some unique features: it is expressed as a Gleason Score⁽²¹⁰⁾. Separate scores (from 3 to 5) are worked out for the grade of the cells and for the patterns they make as they group together. These are added together to make a composite score of between 6 and 10 – the higher the score, the faster the cancer is likely to grow.

The diagnosis of breast, colorectal or prostate cancer at an early stage allows treatment that focuses on minimising the chances of the cancer recurring. This is usually achieved by removing a tumour and, if necessary, using adjuvant therapies (therapies before, alongside or after surgery that increase the effectiveness of the main treatment) to kill cancer cells that might remain inside the body. It is not always possible to stage a cancer with certainty – for example, rectal cancers can be difficult to stage accurately, even with good quality imaging technology⁽²⁰⁸⁾.

3.4 Treatment pathways

For the purposes of this study, the decision was made to restrict recruitment to patients undergoing treatment for a primary cancer with a low to intermediate risk of recurrence with an intent to cure. Further criteria included diagnosis of a primary cancer without metastases, with the first interview at least six weeks beyond surgery or chemotherapy, to allow participants time to recover from the immediate effects of therapy. These guidelines were communicated to the health care specialists who helped to facilitate the recruitment process for this study. These criteria come with a caveat – the details of treatments could not be cross-checked with patients’ medical records, as ethical approvals were based on the student not having access to these. It

is important to clarify that while the participants in this study had been treated with the intention of removing cancer cells from their body, treatment with curative intent is not a guarantee that the disease will not recur – the concept of “cure” in relation to cancer is not definitive. Two participants had not yet received confirmation that their cancer was no longer detectable at the point of their first interview. Neither of these participants were available to participate in a second interview.

Patients were not asked to confirm the details of their prognoses during the interviews, which focused on adaptation after treatment. Progress could only be evidenced by data in second interviews, during which all participants talked in terms of having a good prognosis. To set their experience of treatment in context, the features of primary breast, colorectal and prostate cancers are given below, followed by a description of follow-up treatments and their potential physical effects.

3.4.1 Breast cancer

The majority of breast cancers begin when cancer cells form inside the milk ducts (known as ductal carcinoma), or in the glandular tissue of the lobes (lobular carcinoma). Cancer contained within the ducts or lobes is known as “*in situ*” (IS). Approximately twelve per cent of breast cancers are *in situ* at diagnosis⁽²¹¹⁾. Where the cancer has spread from the ducts or lobes into the surrounding tissue it is defined as “invasive”. Both types of breast cancer can be treated with curative intent if caught early, before the cancer has spread. Some cancers can originate outside of the ducts and lobes – for example, blocking the lymph ducts which drain waste from the cells, resulting in swelling and ridges in the skin. This is known as inflammatory breast cancer, which can spread quickly and is more likely to recur – its poorer prognosis made it inappropriate for inclusion in this study.

3.4.1.1 Potentially curative treatment for breast cancer

The following section outlines treatments for breast cancer undertaken with intent to cure, with reference to NICE guidelines⁽²⁰⁷⁾. Figure 1 (overleaf) shows a timeline of possible treatments in the twelve months after surgery, and the points when participants could be recruited. Radiotherapy and chemotherapy are given after

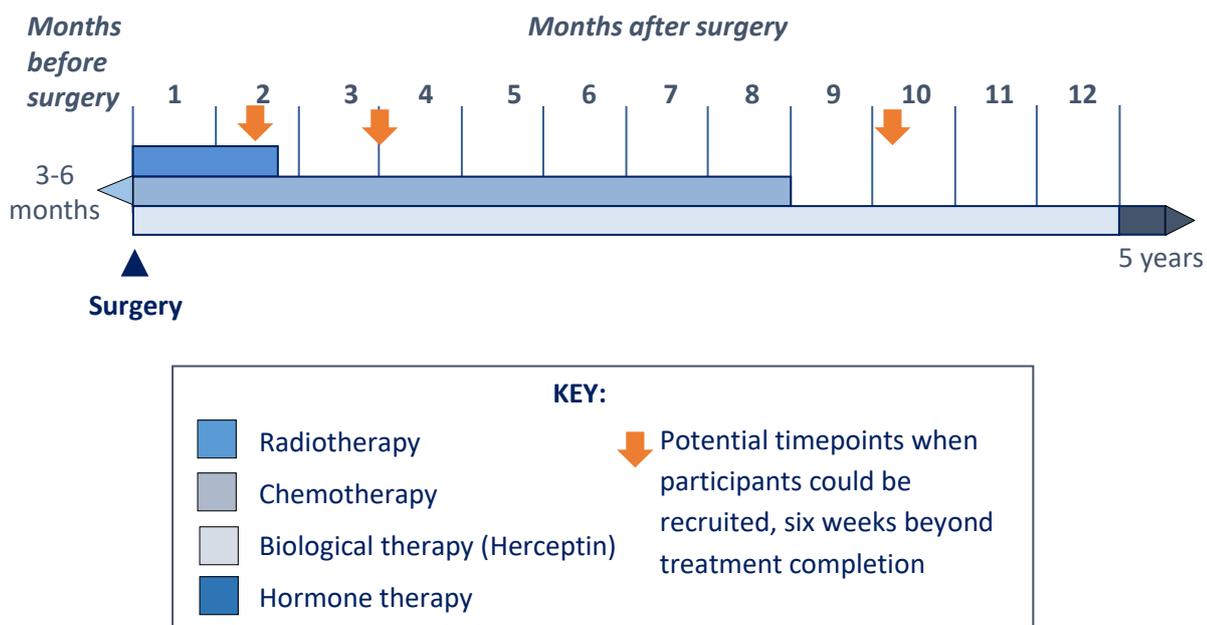


Figure 1 Breast cancer treatment timeline, showing the length of potential adjuvant treatments in the first year after surgery.

surgery when epidemiological statistics relevant to a specific case suggest that there is a possibility of recurrence.

Surgery: Treatment for early-stage ductal or lobular breast cancer begins with surgery. To determine which lymph nodes may be affected, radioactive liquid containing dye can be injected into the cancer – the dye is taken up by the closest nodes first. A decision about whether to remove lymph nodes is taken at this stage. Chemotherapy (see below) is sometimes used before surgery to shrink a tumour – this is known as “neoadjuvant” therapy. Surgery can tackle the cancer in one of three ways: by removing a lump or section of tissue in a self-contained area (a lumpectomy), by removing part of the breast itself (a quadrectomy) or by removing the entire breast (a mastectomy). In cases of early-stage ductal or lobular cancer, surgery can be followed by chemotherapy, radiotherapy, hormone therapy or biological therapy.

Chemotherapy: Tumours can be treated by introducing chemicals into the body which destroy cancer cells or stop their growth. This treatment can also damage normal cells, but normal cells repair over time – cancer cells do not. One drug, or a combination of drugs, can be taken as tablets or injected directly into a vein. Patients usually

undertake between one and five days of chemotherapy followed by three or four weeks off in up to eight cycles; treatment can take several months.

Radiotherapy: The genetic material in cancer cells can be damaged using radiation, causing the cells to die. Radiotherapy is administered by directing electromagnetic rays at the cancer from outside the body (external radiotherapy), or by introducing radioactive material into the body (internal radiotherapy, or brachytherapy), either in liquid form (radioisotope treatment) or in solid tubes placed next to the tumour. Radiotherapy is usually given once a day for between two and seven weeks, with breaks at weekends. Radiotherapy also damages normal cells, but they recover.

Hormone therapy: Hormones can trigger the growth of cancer cells, and drug therapy can inhibit these effects. Hormone therapy for breast cancer blocks the action of the female sex hormone oestrogen. Before the menopause, the ovaries are still producing oestrogen, and luteinising hormone (LH) blockers can prevent the chemical signals that initiate their production. In oestrogen receptor (ER) positive cancers, which contain cells sensitive to oestrogen, the chemical receptor sites can be blocked using the drug Tamoxifen, which can slow down or stop cancer's growth. After the menopause, drugs known as aromatase inhibitors can reduce the oestrogen produced in the body (aromatase is an enzyme which helps the body to produce oestrogen).

Biological therapy: A cellular protein called HER2 is present in high levels in the cancer cells of between twenty and twenty-five per cent of patients, and causes tumours to grow: these are known as HER2-positive cancers. Biological therapy can block the signals sent by HER2, inhibiting the cancer's growth and stimulating the immune system to attack the abnormal cells. This is administered by one-hour infusions of Herceptin via a drip, once every three weeks for twelve months after surgery.

3.4.2 Colorectal cancer

Colorectal cancer refers to cancer of the bowel or the rectum – it is also known as bowel cancer. The lining of the bowel, the mucosa, is made up of gland cells and skin-like (“squamous”) cells. Ninety-five per cent of colorectal cancers begin in the gland cells (they are known as adenocarcinomas); squamous cell cancers are rare. The

anastomosis. For an anastomosis to heal, a section of the bowel might need to be temporarily attached to the outside of the abdomen with an opening for faeces to pass out of the body, so that the process of digestion bypasses the area. In the small bowel this is known as an ileostomy; in the large bowel it is a colostomy. A purpose-made waterproof bag is attached to the opening (stoma) to collect bowel contents. This can be reversed after a few weeks or months, unless the tumour necessitated the removal of a large section of the colon or rectum. Rectal cancers are surgically removed along with a border of healthy tissue. The fold of tissue anchoring the intestines to the abdominal wall (the mesentery) can also be removed, as this may contain cancer: this is known as a total mesenteric excision. Rectal cancer can also require a temporary or permanent colostomy; temporary colostomies are reversed after about eight weeks.

Radiotherapy and chemotherapy: Radiotherapy is not usually used to treat cancers of the large bowel, but is used to treat rectal cancer to shrink tumours in preparation for surgery. This is sometimes carried out in combination with chemotherapy, which sensitises the cancer cells to radiation (“chemoradiotherapy”). Chemotherapy is given as injections, or as an infusion through a drip, or can be given in tablet form (a drug known as capecitabine) during radiotherapy. External radiotherapy is usually given daily, with a break at weekends, with the length of treatment determined by the size of the tumour. Internal radiotherapy (brachytherapy) can also be used to deliver a high dose during one or two short treatment sessions, using a radioactive tube placed close to the tumour. There is a break of a few weeks between chemoradiotherapy ending and surgery taking place, to allow the body to recover. Chemotherapy is sometimes carried out after surgery to minimise the chance of recurrence, but is not usually necessary for people with early stage bowel cancers.

3.4.3 Prostate cancer

The prostate is a gland encircling the urethra on the underside of the bladder in men. It secretes the white, alkaline liquid that surrounds sperm to make up seminal fluid (this increases the survival time of sperm by counteracting the acidic environment in the vagina). Cancerous tumours in the prostate usually grow slowly, over a period of years. Their presence can sometimes be detected by measuring levels of a substance in the

blood that helps to liquify seminal fluid – this is known as prostate-specific antigen (PSA). Higher than average levels of PSA can indicate health disorders in the prostate, including cancer. Localised cancers (tumours that have not spread outside of the gland) can be low, medium or high risk depending on their staging, grading and PSA level. The risk level determines the treatment. If cancer cells have broken through the tissue surrounding the gland (known as locally advanced prostate cancer) or have spread to other sites in the body, treatment focuses on controlling the symptoms.

3.4.3.1 Surveillance and potentially curative treatment for prostate cancer

Localised prostate cancer does not always require treatment. More than forty per cent of cases are first diagnosed in men aged between fifty and sixty-nine, and fifty per cent of cases in men aged seventy or over⁽²¹³⁾, and if a tumour grows slowly it may never become large enough to cause symptoms. Early-stage, localised prostate cancers are often observed rather than actively treated (this is known as active surveillance). For tumours that need treatment, surgery can be performed to remove the prostate gland. Alternatively, radiotherapy alone may be used to try to cure the cancer. Figure 3 (opposite) shows a timeline for the treatment and surveillance of prostate cancer.

Active surveillance: Active surveillance is the monitoring of cancer that is completely contained within the prostate gland. In the first year after a diagnosis of low risk localised prostate cancer, NICE guidelines advise PSA testing at three- to four-month intervals⁽²⁰⁹⁾. A clinician will also examine the prostate by hand – the gland can be felt through the wall of the rectal passage (this is known as a digital rectal examination, or DRE). After twelve months, a second biopsy of the prostate tissue will be taken to check for cancer cells. Surveillance aims to detect when the cancer is growing, which would indicate a need for surgical treatment or radiotherapy in an attempt to cure it. Localised cancers that are growing very slowly are not treated, as they may never cause symptoms, and the side effects of surgery and radiotherapy can seriously affect quality of life (see section 3.5, below).

Surgery: Curative surgery for localised prostate cancer involves the removal of the prostate gland and the tubes that carry semen (the seminal vesicles). The operation is known as a radical prostatectomy, and can be performed using keyhole surgery.

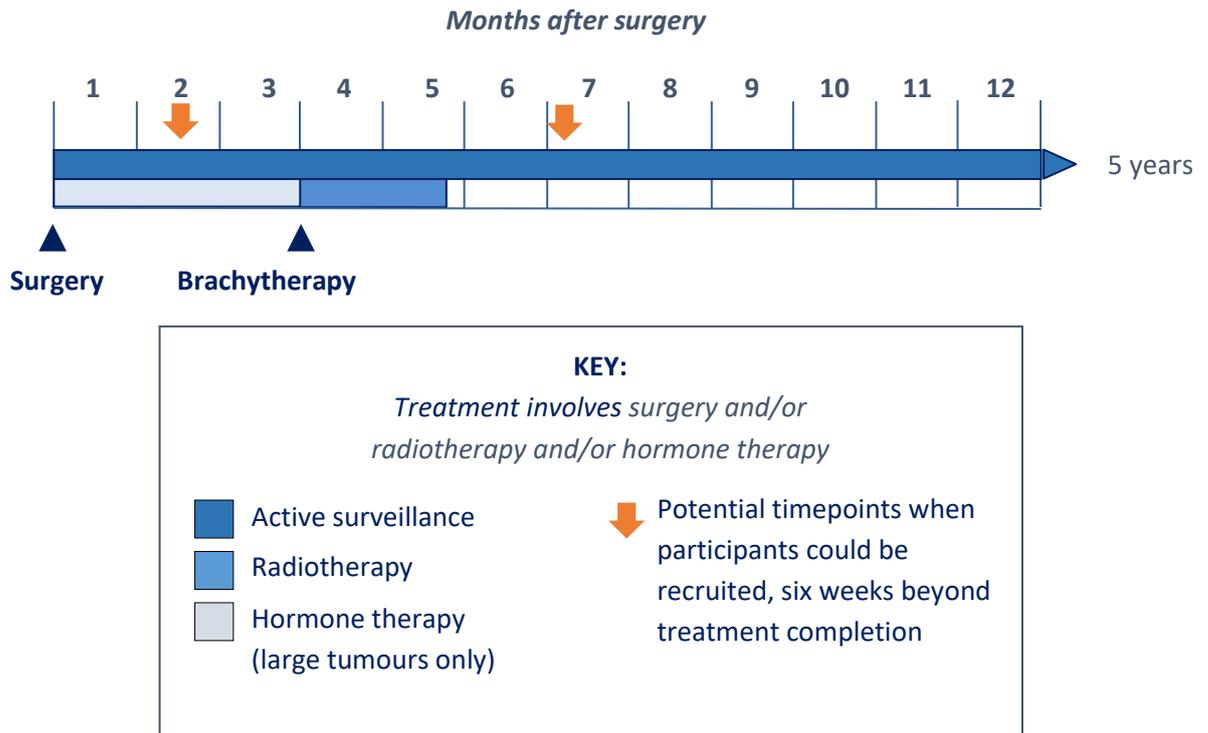


Figure 3 Prostate cancer surveillance and treatment timeline, showing potential approaches to intermediate risk prostate cancer. Treatment involves surgery and/or radiotherapy; hormone therapy can be used to shrink tumours.

Radiotherapy: Early-stage localised prostate cancers can be curatively treated in more than sixty per cent of cases using external radiotherapy to deliver a high dose of radiation (this also known as radical radiotherapy). They can also be curatively treated using brachytherapy (internal radiotherapy). In low dose rate brachytherapy, between eighty and 120 very small metal tubes known as “seeds” are permanently implanted into the prostate gland – the seeds are radioactive, but the radioactivity does not travel far outside of the prostate and wears off after a few months. In high dose rate brachytherapy, a quicker form of treatment, small radioactive tubes are inserted near the back of the prostate and left in place to deliver a dose of radioactivity, and are removed at the end of the treatment session. High dose rate brachytherapy is usually used alongside external radiotherapy. If cancer has spread into the tissue covering the prostate, external radiotherapy can be used to try to cure it. Radiotherapy will be used on the tumour and on an area up to two centimetres around it, to ensure the treatment of any cancer cells not picked up on the scan.

Hormone treatment: A high PSA or Gleason score, or a tumour that has spread into the tissue around the prostate, can be treated using drugs to block the effects of the male sex hormone testosterone, which makes the cancer grow. Treatment may occur before, during or after radiotherapy. The drugs stop the chemical messages telling the testicles to produce testosterone. They are given as injections once a month, once every three months, or once a year. Alternatively, anti-androgen tablets can be used to prevent testosterone from the testicles reaching the prostate.

3.5 The short and long term physical effects of treatment

Unwanted physical effects can arise from the treatments given for cancer. These are experienced in different ways by every individual, dependent upon their general health and the type of treatments they are undergoing. Common physical effects that can persist in the months following treatment are outlined below.

Fatigue: All cancer treatments can cause fatigue – severe, chronic tiredness that is not remedied by resting. Surgery causes stress to the body, and tiredness is experienced alongside the healing process. Chemical substances from radiotherapy, chemotherapy and hormone therapy often cause fatigue as a side effect. For example, chemotherapy causes the number of red blood cells in the body to drop, lowering the amount of oxygen delivered to the tissues and causing a lack of energy.

Post-surgical pain and discomfort: Surgery can cause localised scarring, pain and nerve damage. Breast surgery wounds can take about three weeks to heal; reconstruction, in which skin from another part of the body can be used to replace breast tissue, can lead to further surgery if the inserted tissue fails to connect with the existing blood supply. Surgery for colorectal cancer can change bowel habits; where it requires a colostomy or ileostomy (creating a hole in the abdomen through which waste products leave the body), this has to be managed by the patient at home. Surgery can also cause adhesions, where bands of new tissue form between the bowel and surrounding tissues, or a hernia where part of the bowel squeezes through other tissues nearby. Keyhole surgery to remove the prostate gland can cause long term difficulties with controlling urinary flow if the muscles around the bladder are damaged. Pelvic radiotherapy can also cause functional problems in the bowel and bladder.

Difficulties with sexual functioning and fertility: Surgery or radiotherapy for men suffering from rectal cancer or prostate cancer can cause long term impotence by damaging the nerves and/or blood supply that control erectile functioning. After prostate cancer treatment, sexual difficulties resulting from damaged nerves affect up to forty per cent of men⁽²⁰³⁾. Small prostate cancers sited away from the nerves responsible for erectile function can sometimes be removed without causing damage, but this procedure risks leaving cancer cells inside the body. In women, treatment for breast cancer or colorectal cancer can cause changes to the menstrual cycle, or early menopause and infertility. Treatment-related fatigue and a lowering of libido caused by cancer drugs can have effects on sexual function in both men and women.

Lymphoedema (swelling): Body cells are surrounded by a fluid containing water, nutrients, hormones and waste products. This circulates between the tissues and the bloodstream via a network of vessels and filtration glands (lymph nodes), which collect the fluid and filter it back into the blood. Surgery and radiotherapy can damage lymph nodes, leading to chronic swelling, usually in the arms or legs. There is no cure for lymphoedema, but it can be controlled through specialist massage, and by keeping the skin clean and avoiding infection.

3.6 Chapter summary

The aim of this study is to investigate how social and material resources, and the meanings associated with them, shaped people's experiences in the year beyond treatment. While this draws away from the focus on embodiment that dominates current literature about adaptation and recovery after cancer, the intention of this chapter is to provide a backdrop that acknowledges the physical impact of treatment. To answer the research questions outlined at the end of Chapter 2, the study intended to recruit people who were at the point of leaving specialist care after potentially curative treatment for a primary cancer of the breast, colon or prostate. This chapter has outlined the treatment protocols for these primary cancers, and their associated short and long term physical effects – the medical procedures and symptoms that may be familiar to potential participants.

Chapter 4: Methods – Rationale, research design and recruitment

The goal of interpretive research is to understand the actual production of meanings and concepts used by social actors in real settings. A relativist stance is adopted such that diverse meanings are assumed to exist and to influence how people understand and respond to the objective world. Interpretive research thus describes how different meanings held by different persons or groups produce and sustain a sense of truth.

Gephart, 2004^(214, p456-7)

4.1 Introduction

A study examining the personal meanings associated with illness could take one of a variety of methodological pathways. This study aimed to provide an in-depth analysis of individual experience, with deliberate attention to the social and material resources which mediate this experience. The choice of methods was based on two key concerns: the aim to develop theory that might usefully inform the development of sensitive follow-up services, and the necessity of keeping social context central to the study. This chapter situates the study among broader debates about methodology, and outlines the rationale behind the choice of research methods. It begins by considering the purpose of research praxis, and ongoing debates about epistemological and ontological assumptions. It then considers the type of knowledge that this study has set out to discover, outlining its theoretical framework and how this underpins the research design. The chapter concludes with a description of the recruitment process and ethical considerations, and a reflexive discussion acknowledging the perspective of the PhD student. A description of data collection and analysis follows in Chapter 5.

4.2 Research praxis: positioning the paradigm debate

All research has a common purpose: the systematic investigation of phenomena with the aim of gaining new knowledge, and the use of this knowledge to generate theories about the world, and (where possible) to develop our practices within it. The

debate about the philosophical frameworks that structure research, based on “the great divide”^(215, p14) between objectivism and subjectivism, has been well rehearsed since Kuhn’s characterisation of the paradigm wars in *The Structure of Scientific Revolutions*⁽²¹⁶⁾. Layers of this debate have been laid across the social sciences: the discipline has been characterised as methodologically deficient in subscribing to subjectivist approaches⁽²¹⁷⁾, and at the same time criticised for its naive adoption of positivism^(215, 218).

Polemic arguments – for example, that constructivism is a fallacy⁽²¹⁹⁾, or that objective truth is an ungraspable chimera⁽²²⁰⁾— carve out opposing niches of expertise. The concept of toleration between perspectives, given a high premium in many debates, is depreciated in value by the continual reworking of epistemological conflicts. Imposing a marked divide between methods leads to an oversimplified characterisation of quantitative and qualitative techniques as belonging, respectively, in the objectivist versus subjectivist camps. As Willig and Stainton-Rogers point out⁽²²¹⁾, the epistemological boundaries of quantitative and qualitative methods are successfully blurred in some techniques – for example, content analysis (which calls for the quantification of thematic concepts) and Q-Methodology (which employs ranking and factor analysis to process qualitative data).

Within wholly qualitative approaches, research continues to fracture along sharp methodological boundaries – dependent, for example, on the researcher’s position on the balance between individual agency and the determinism of social structures, or on disagreements about the usefulness of co-constructed interview data in comparison to naturalistic conversation⁽²²²⁾. Methodolatry can emerge from these polemics – the reification of particular techniques as the only pathway to truth^(223, 224). This can encourage an attention to methods as an end in themselves, rather than as practices situated within particular philosophical frameworks.

More than twenty years ago, Becker pointed out that the work of worrying over the epistemological debate is perhaps best continued by philosophers of science⁽²²⁵⁾. Continuing to focus on the metaphor of the great divide does little to advance the common purpose of research praxis. Situating arguments on either side of a divide is a political act that delegitimises some types of knowledge by virtue of their metaphorical

position. As Hammersley has pointed out⁽²²⁶⁾, pursuing this process of deligitimisation – “redefining knowledge to mean *illuminating fictions* or *partisan perspectives*”, author’s italics^(p581) – implies a loss of functionality for social science.

This thesis takes the stance that objectivist and subjectivist approaches share the common aim of gleaning knowledge, that this knowledge is multifaceted, and that chasing a gold standard of supposed empirical truth is only one of many positions from which we can advance our understanding of what it is to be human. No individual methodological pathway should be credited with a monopoly on progressing knowledge in the social sciences.

4.3 The choice of research methods

The choice of methods for this project emerged from its aim to investigate the personal meanings and motivations connected with adaptation to life after cancer treatment with curative intent. The research seeks to understand, contextualise and theorise rather than to reduce, quantify and verify. The starting point for its methodology emerges from the following premises:

- that human experience is characterised by the attribution of meanings to the things around us, illness being just one facet of this experience, and that we use these meanings to make sense of the world and to shape our expectations about the future;
- that we cannot ignore the role of structural factors in shaping human experience, and that an attention to participants’ everyday environments will allow a focus on social context and the meanings surrounding this experience; and
- that we can access personal meanings and their potential connections with social and material context through semi-structured interview dialogue.

4.4 A statement of epistemological and ontological assumptions

Epistemology is a philosophical theory that considers what might count as knowledge⁽²²⁷⁾ – for example, whether we are accessing credible understandings when

we examine statistical outcomes or subjective experience. Ontology is the study of social reality or “being”⁽²²⁸⁾, and considers whether the world exists in a structured, objective sense, or whether it is unstructured and we interpret or construct its nature dependent upon our cultural and social frames of reference⁽²²⁷⁾. This study is situated within an epistemological framework of social constructionism. The constructionist perspective takes a critical stance towards the positivist assumption that our observations of the world are objective and unbiased⁽²²⁰⁾.

Social constructionism construes knowledge and meaning as phenomena that we construct during our social interactions, and as situated—specific to the time, place and culture in which they are produced⁽²²⁹⁾. The role of these situational factors in constraining behaviour is given more or less credence in different approaches to qualitative research⁽²²⁷⁾: in this study they are acknowledged as an influence on meaning-making and behaviour. Within this framework, the focus of this project resonates with the philosophical approach offered by symbolic interactionism⁽¹⁰⁸⁾. Symbolic interactionism posits that our actions are shaped by the meanings that we ascribe to other people, and to physical objects and concepts in the world, and that these meanings emerge through our interactions with others and our interpretations of experience.

This study investigates how people make meaning from their experience of cancer, and how they use these meanings and the social and physical environments around them to adapt to the changes that cancer brings. In comparing findings with the extant literature examining adaptation to life after cancer treatment, it aims to illuminate how these meanings might converge with or diverge from the generalised meanings currently accepted in the field. It intends to move aside from defining people with a history of cancer through the concepts currently associated with survivorship, acknowledging that the lived experience of cancer survival is changing for patients with good prognoses, and examining individual imperatives towards adaptation in the light of these changes.

The interpretivist philosophical framework for the project is put forward as a coherent way of examining human understandings of the experience of illness and how these are affected by social context and the lived environment. It also subscribes to the

belief that we can improve the care that we provide for people by gaining new insights into the lived experience of illness, and using these insights to extend the range of responses we might make to it.

4.5 Research design

The aim of this study was to focus on the meanings that shape people's approaches to adaptation and recovery, and on how these are mediated by their everyday resources. One intended outcome was to outline a localised theory of adaptation to life after potentially curative treatment for cancer, based on the social and material resources available to people in their local and domestic environments. Qualitative work cannot aim for generalisability in the way that quantitative work can⁽²³⁰⁾ – in developing a localised theory the intention was to provide a model with a level of transferability to the experiences of other patients in similar circumstances. The development of health services sensitive to people's individual situations could include suggestions to help patients examine the resources they already have (whatever their social and economic status), and how these might be used to make the experience of adaptation easier. While interpretations of the embodied experience of illness may refine our understanding of patients' needs, they do not make suggestions about how to use existing everyday resources to facilitate recovery, and how other people (both lay and medical) can support this process in a way that works for the patient.

4.5.1 Theoretical framework

A variety of theoretical frameworks were considered for the project, including phenomenology and discourse analysis. Phenomenology provides detailed analytic protocols for examining lived experience. Its existential philosophy focuses equally on lived space, temporality and embodiment, in addition to relationships and the immediate environment, and emphasises the agency of the participant. For example, van Manen's "life worlds" approach⁽²³¹⁾ considers lived time, space, body and relationships as key analytic concepts. It was felt that a focus on embodiment and agency might draw away from the central issue at stake in this study – the mediating influence of social and material resources on adaptation after treatment. A discursive

analysis would focus on the ways that participants talk about and interpret the self and the social worlds they participate in⁽²³²⁾, but it would demand a fundamentally different approach, the aim of which would be (in Hammersley's words) "to generate displays of discursive practices, rather than to elicit information about the world or about people's individual subjectivities"^(233, p259).

Capturing the interplay between subjective experiences of illness recovery, the social processes and material resources woven through these experiences, and the meanings made from all of these phenomena, required a different approach. The chosen approach would need to embrace individual subjectivities, and allow a deliberate analytic attention to social processes and the contextual issues that mediate them. Recent versions of grounded theory^(234, 235) offered a close fit.

4.5.1.1 *Grounded theory*

Grounded theory is a rigorous, well tested approach to analysis in health research, with a specific focus on the issues central to this study. It began in a realist paradigm⁽²³⁶⁾, but has been moved beyond these epistemological origins by Charmaz to encompass constructivist philosophy^(235, 237), and by Clarke's supplementary analytic techniques, which focus on social settings alongside social processes⁽²³⁴⁾. Clarke situates her work within social *constructionism* – a philosophy that sees knowledge as produced (or constructed) within social interactions; this is subtly different from Charmaz's background of *constructivism*, which focuses on the role of sense-making within the individual as a basis for action. These viewpoints have been combined in Clarke's grounded theory techniques.

Strauss and Corbin's version of grounded theory^(238, 239) uses the philosophical approach of symbolic interactionism as a backdrop for analysis. Symbolic interactionism focuses on the way that the meanings we attach to other people, objects and concepts in the world around us are driven by our social interactions⁽¹⁰⁸⁾, and in George Mead's view of the self as something that we shape through these interactions⁽²⁴⁰⁾. Clarke⁽²³⁴⁾ elaborates on the way that individual perspectives emerge from collective social discourses and the positions that these discourses make available to us. Research into contextual detail must necessarily combine the individual and the

social, and this project takes interactionist perspectives and recent constructionist developments in grounded theory as its philosophical starting point.

Interpretations of symbolic interactionism include the concept of social worlds – universes of discourse focused around a central activity^(239, 241). Within the arena of cancer there are multiple social worlds defined by their common activities – for example, the scientific world which searches for biochemical treatments and refines them through clinical trials, the patient-facing world of oncology which dispenses diagnoses and treatments, the world of the media (inhabited by a subworld of cancer charities) which generalises and defines the cancer experience, and the patients’ world, within which embodied experiences of suffering are shared. Some worlds are situated in institutions (hospitals, clinics), others have no material venue (such as the world of cancer “survivors”). An early social worlds theorist, Shibutani⁽²⁴¹⁾, pointed out that “what a man [*sic*] does depends largely on his definition of the situation”^(p563), and that these definitions are shaped by the norms and values of the social worlds we inhabit: our meaning-making is inextricably linked with how we behave.

4.5.1.2 *Situational analysis*

Traditionally, grounded theory has focused on action and process, with the human subject of the research at the centre⁽²⁴²⁾. In analysis, using gerunds to code can focus attention exclusively on the perspective of the participant at the cost of exploring how their perspective might be constructed around, or informed by, structural constraints such as social interaction and material resources. Clarke⁽²³⁴⁾ argues that in addition, “fresh methodological attention needs to be paid to *nonhuman objects* in situations – things of all kinds...cultural objects, technologies, animals, media, nonhuman animate and inanimate pieces of material culture, and the lively discourses that also constitute the situations we study – from cups and saucers to lab animals to TV programmes” (author’s italics)^(p91). This called for a push “around the postmodern turn”^(p19), bringing an additional attention to social structures and everyday talk, and how these interweave with lived experience at the individual level.

Clarke’s method, known as situational analysis, draws out Strauss’s earlier emphasis on social worlds^(234, 239) and supplements Charmaz’s constructivist approach^(235, 237) with

visual mapping techniques. These maps provide a framework for drawing out human, nonhuman, discursive and material elements in the situation on which the research is focused. It is a technique primarily applied in studies encompassing multiple sources of data such as institutional documents, fieldwork notes, interviews, newspaper articles and reflective journals⁽²⁴²⁾, and is driven by theoretical sampling to explore variety and difference alongside commonality. Smaller scale projects such as this PhD study, with its single source of data, do not fully exploit Clarke's techniques – their analytic range is narrower than the method allows. However, the mapping techniques extend the reach of constructivist grounded theory: for this project, they had potential for sensitising the analysis to the social and material resources that affected participants' experiences and meaning-making, and for exploring counterpoints in the data.

4.5.1.3 Breaking with tradition

The earliest forms of grounded theory traditionally positioned the literature review, and the application of theory previously developed within the substantive area of the research, as processes that should occur after analysis so as not to influence the findings^(236, 243). More recent approaches acknowledge the impossibility of theoretical naivety at the outset of a research project^(125, 234, 235, 244). This is particularly relevant in sociological research exploring cancer, in which a considerable corpus of literature now exists in the academic and public domains with the potential to influence researcher and participants alike. It could also be argued that there is a danger for early career researchers in lacking sensitisation to previous theories, as they might miss potential subtleties in their data or re-examine concepts which are already analytically overworked.

A deliberate distinction can be made between sensitisation and the *a priori* application of theoretical concepts to new data^(108, 237). In this project, the literature review was updated and reworked after the study findings had been written up, and section 2.2 of the review (*Setting the scene: theoretical frameworks*) was conceived at the point of the update. Links between the findings and theoretical ideas in the literature became clear in retrospect, rather than shaping the analysis in the first instance.

4.5.2 Choosing photo elicitation

The decision to use participant photography was based on the premise, detailed in Chapter 1, that social context is a mediating factor in people's experience of disease and recovery. The experience of cancer is not entirely situated within health care institutions: temporally speaking, contact with health care professionals is a smaller part of the story than the way that illness and recovery play out in the home. "Real life" experience is not only about significant events and the words we use to describe them – it is multidimensional⁽²⁴⁵⁾, inherent in the visual as much as the verbal.

Experience is what we see and feel as much as what we talk about and do: it is shaped by social interaction, but is situated as much within the people and the objects we choose to have close to us and in the spaces we move around in as it is within the self.

Clarke⁽²³⁴⁾ argues that we need to enlarge our focus to encompass not only participants' intrapersonal experience (what happens within the mind), but the interpersonal, discursive, cultural and material ("nonhuman") elements that weave and shape this experience. Participant photography helps to turn the focus of an interview outwards – to objectify lived experience, to separate self from surroundings⁽²⁴⁶⁾. In this project, participants were asked to consider their environments, the role of material objects, and (in photographing representations of people, places of work, or medical institutions, for example) the everyday talk that shaped their perspectives on life. The photography provided an opportunity to access private worlds⁽²⁴⁷⁾, allowing a window into the environments where recovery played out. In explaining photographs, we attribute or associate meanings with images⁽²⁴⁸⁾, and meaning-making was crucial to the understanding of social context in this study.

The argument that the semi-structured interview can privilege the researcher's agenda is well rehearsed^(227, 249, 250), and a frequently quoted justification for the photo elicitation method is that it shifts control of the agenda towards the participant^(246, 251). Photo elicitation helps to push the interview beyond the boundaries of a fixed location and time in two distinct ways: by providing a space where experiences that occur outside of the interview can be recorded, and by allowing time for the participant to interpret significant moments or materialities prior to interview. In the act of deciding what to photograph, participants have room to experiment with the people, moments,

objects and places that have been significant to the experience at the centre of the research. This experimentation allows the participant's interpretation of what is significant to take centre stage in subsequent interview dialogue.

4.5.2.1 Limitations of photo elicitation

The limitations of photo elicitation have been widely discussed in the literature. There is a tendency to regard photography as a common social skill⁽²⁵²⁾, but some people can find it an uncomfortable method of expression. Undertaking photography can be time consuming for both researchers and participants^(248, 253), necessitating the transfer and stewardship of cameras and images, potentially at multiple time points. Participants can develop a burdensome preoccupation with carrying out photography "correctly" to an imagined prescription from the researcher, regardless of reassurance that this is unnecessary^(246, 254). Choices made by the participant at the point of production of the images can be biased towards an imagined audience⁽²⁵⁵⁾; they may also choose to involve other people in these choices⁽²⁵⁶⁾.

Once the photographs have been produced, they have the ability to provoke strong emotional responses during an interview^(251, 253, 256), which must be addressed in an ethical manner by the interviewer. There is a danger that tangents not relevant to the research will arise as images are considered, and the interviewer has to be prepared to rescue this situation and guide participants politely back to the topic in hand⁽²⁴⁸⁾.

Images of people raise ethical questions about confidentiality, and it can be difficult to balance the unwillingness of some participants and the active desire of others to be associated with the data^(255, 257), in particular in the face of ethical review boards who insist that blanket confidentiality is the only safe solution. For this project, a separate consent form for images allowed participants to specify any photographs which they did not wish to be shared in the dissemination process (see Appendix 2).

4.6 Participant selection and recruitment

A convenience sample was recruited via hospital outpatient clinics (detailed below). Criteria for eligibility demanded a diagnosis of a primary cancer and recent potentially curative treatment, and this was best achieved by targeting potential volunteers

through medical channels. No limitations were imposed in terms of age, social status or comorbidities. Recruitment took place via five outpatient departments at a cancer unit in a large city with approximately 250,000 residents: two oncology outpatient clinics (one a breast clinic, the other a general clinic for breast and colorectal patients), a specialist nurse unit, urology outpatients and the radiotherapy department.

Breast clinic: For a period of six months (February to July 2014), the researcher attended the breast clinic once a week with the agreement that consultants would pass on participant information sheets (Appendix 3) to eligible patients at discharge appointments and direct them to the researcher in a separate room. Laminated posters about the project were also displayed in the clinic with the help of the sister in charge (Appendix 7). No patients from this clinic expressed an interest in the study.

Oncology outpatients: Recruitment of breast and colorectal cancer patients took place at an oncology outpatient unit across nine months (August 2014 to April 2015), assisted by an oncology consultant who brought patients who met the study criteria to a separate room to introduce them to the researcher at the end of their discharge appointment. The researcher conducted this first meeting alone with potential participants; a minority of patients brought family members into the room. The study's design and aims were explained in lay language, participant information sheets and the photography brief (Appendices 3 and 4) were given to patients with an opportunity for them to read the information and ask questions. Twenty patients were recruited through this clinic; all were keen to participate. They were asked to sign consent forms for interviewing and photography (Appendices 1 and 2), and were given a digital camera to take away. First interviews were arranged for approximately two weeks beyond this meeting to allow time for photography.

Specialist nurse unit: For a period of eleven months (April 2014 to February 2015), a colorectal cancer nurse specialist gave eligible patients information sheets and talked to them about the study, and agreed to pass details of interested patients on to the researcher. One participant (Ellie, see Table 3, p75) was secured through this unit – the researcher telephoned to arrange a consent visit at Ellie's home to explain the photographic brief and offer the opportunity to ask questions. Consent forms were signed, a camera was given, and the first interview date was agreed at this visit.

Urology outpatients: A urology consultant agreed to pass on patient information sheets to prostate cancer patients at discharge appointments, and fifty leaflets were left with the department. No participants were recruited via this clinic.

Radiotherapy department: An arrangement was made with the manager of the radiotherapy unit to distribute study information to prostate cancer patients. Patient information sheets for the study were included in discharge information packs for eligible prostate cancer patients by the radiotherapy department over a period of eleven months (April 2014 to February 2015). Approximately ten to fifteen leaflets were distributed each week. In this time, seven participants contacted the researcher offering to take part. The researcher telephoned to arrange a consent visit at each participant’s home to explain the study and offer an opportunity to ask questions. All volunteers agreed to take part; consent forms were signed, cameras distributed and first interview dates agreed during these visits.

In total, twenty-eight participants agreed to take part during the time available for recruitment. One breast cancer participant dropped out, unable to make time for an interview. One colorectal cancer participant in his nineties died during the two weeks between consenting in the outpatient department and the interview date.

4.6.1 The sample

Table 3, opposite, outlines details of the sample in the order in which they were interviewed within each cancer type. Participants were not asked for details of their income, but an indication of relative levels of affluence was taken from mapping their postcodes against the indices of deprivation (see Figure 4, below). The range across the indices occurred by chance, as recruitment was open to any patients who met the study criteria, regardless of their social background.

	<i>Most affluent areas.....Most deprived areas</i>									
<i>Deprivation decile:</i>	10	9	8	7	6	5	4	3	2	1
<i>No. of participants:</i>	6	4	2	2	2	3	0	2	1	4

Figure 4 *Participants’ postcodes mapped against the indices of deprivation.*

Pseudonym (number of interviews)	Age	<u>M</u> arried/ <u>S</u> ingle/ <u>W</u> idowed	<u>W</u> orking/ <u>R</u> etired/ <u>U</u> nemployed	Treatment* (comorbidities) as reported by participants	Residential location: <u>R</u> ural, <u>U</u> rban <u>S</u> uburban (Deprivation decile**)
BREAST CANCER PARTICIPANTS (10)					
Lesley (2)	43	M	W	C, S/L, H	U (8)
Maura (1)	81	S	R	S/L, H (diabetes)	U (6)
Clare (2)	55	M	W	C, S/L, H	U (5)
Gill (2)	40	M	W	C, S/L, H	U (3)
Mary (2)	70	S	R	R, H	U (2)
Laura (2)	46	S	W	S/L, R, H	U (5)
Harriet (2)	72	M	R	S/L, R	S (10)
Liz (2)	48	M	U (by choice)	S/L, R, H	U (1)
Eleanor (2)	71	M	W	S/L, R, H	R (9)
Janet (2)	70	M	R	S/L, C, R, H	U (8)
PROSTATE CANCER PARTICIPANTS (7)					
Tony (2)	69	M	R	S, R	R (7)
Pete (1)	75	S/W	R	R, H	S (10)
Martin (1)	72	M	R	R, H	S (9)
Stephen (2)	84	S/W	R	R, H	R (5)
Jack (2)	65	M	R	R, H	S (10)
Arthur (2)	77	M	R	R, H	U (1)
Greg (1)	78	M	R	S, R, H (mild epilepsy)	S (10)
COLORECTAL CANCER PARTICIPANTS (9)					
Derek (2)	81	M	R	IR (stroke)	U (1)
Fiona (2)	69	M	R	C, IR	S (9)
Will (2)	75	M	R	C, S + stoma (diabetes)	U (7)
Ellie (2)	64	S	W	S	U (6)
Layla (1)	44	M	W	S, C, R	R (10)
Mark (1)	62	M	W	C, IR	U (3)
James (1)	75	M	R	R (heart condition)	U (1)
David (1)	80	M	R	C, R	S (10)
George (1)	82	S/W	R	S, C, R (early dementia)	R (9)

*Treatment types: (S) surgery; (L) lumpectomy; (R) radiotherapy; (IR) internal radiotherapy; (C) chemotherapy; (H) hormone medication (comorbidities in brackets).

**1 = top 10% most deprived areas; 10 = top 10% most affluent areas.

Table 3 Details of the twenty-six study participants.

4.7 Ethical considerations

Ethical approvals for this study were granted on 31st July 2013 through proportionate review by the London City & East NRES Committee and the NHS Health Research Authority, REC reference 13/LO/1167, IRAS project ID 129549 (see Appendix 8). The project was sponsored by the University of Hull. A Research Passport was obtained to enable the PhD student to recruit on hospital premises. The student did not have direct access to patients' contact details unless they were provided voluntarily by patients. Initial contact was mediated by secondary care staff, who introduced the project to patients. Contact between patients and the PhD student was facilitated only when patients expressed an interest in taking part, and talking with the student did not put them under any obligation to do so. Patients were asked for their GP details at the end of their first interview; prior to contacting patients for second interviews, their GPs were contacted to verify that they were well and it was suitable to approach them.

Cancer is an emotive subject, and there was the potential for participants to become upset in talking through their experiences. The hospital where recruitment took place had on the premises an oncology health centre, which provided drop-in care for patients with psychological concerns. Prior to the study commencing, the student met with the lead psychologist at this unit to introduce the study and secure agreement for psychological support for any patients taking part in the study who might require it.

(None of the participants took up this support in connection with the study.)

Emotional upset during interviews only occurred with two participants, Ellie and Layla (both had colorectal cancer treatment). In both cases, the interview was stopped and the tapes switched off – both expressed their wish to continue after a break. Layla's initial prognosis had been frightening (she subsequently responded well to treatment), and Ellie struggled with having to take her diagnosis on trust – her cancer was picked up from a screening test and she had not suffered any symptoms. Their episodes of distress came about through talking about these situations, and were not provoked by the photographic images they took. This study focused on social and material and resources for recovery, rather than on the self and embodiment issues – participants responded to this by taking an assets-based approach to describing their situation, and the majority did not experience distress during the interviews.

4.7.1 Images and ethics: the use of participant photography

Further ethical issues were introduced by the use of participant photography. The literature exploring ethical issues in research using photography focuses on consent, confidentiality and the ownership of images. In this study, two participant consent forms were prepared – one for the interview, and one for the photographic material (Appendices 1 and 2). The photography form asked for participants' consent to use images in dissemination, specified that no photographs of identifiable people would be included in dissemination, and asked participants to list any further photographs that they did not wish to be reproduced in material related to the study. Only one participant specified photos in this section of the form – she did not wish any images of her local area used, in case this might identify where she lived. Participants were aware that the ownership of images would be extended to the researcher, that the images included in this thesis would be available through the university, and that photographs might be used in publications and presentations about the research.

One further vital issue reflects across all of the considerations above: the need for ethics boards to consider the practical context of a research project, and where studies use visual methods, to allow for flexibility in this area of the protocol. Clark⁽²⁴⁵⁾ argues that the universal principles behind the predetermination of protocols by ethics review boards is not adequate for visual methods – that projects involving visuals demand “situated ethics”^(p68), which take into account contextual circumstances and their relevance in making decisions about ethics on-the-ground when research is in practice. One example of how things could have been conceived differently emerged from the expression by some participants in this study of a willingness to be identified in photographs. I explained that the ethical framework for the study made this difficult (ethics boards for health/medical studies assume that confidentiality is imperative for participants), and that the blanket approach of confidentiality for all was judged to be in the best interests of the majority of the participants.

Confusion over the responsibility for confidentiality led two participants (Lesley and Jack) to avoid taking pictures of people entirely, when part of the focus of the project was interaction with others. In retrospect, the issue of internal confidentiality (the ability of people who know participants well to recognise them from photographs of

their home and locality) could have been reinforced further with participants, and this issue has to be considered sensitively in dissemination. I also did not anticipate requests from participants to send digital images back to me via e-mail – several participants suggested this (and were unworried by it), and had to be refused.

4.8 Reflexivity: the student's perspective

At the time of the study, the PhD student worked as a Research Associate in a medical school, having requalified in psychology and research methods after working in publishing for several years. Previous experience of working in research included eight years spent as a research assistant across a variety of projects in applied health and education. Experience of interviewing vulnerable patients had been gained across three large-scale qualitative projects evaluating end of life care. Participants in this PhD study had good prognoses, but a sensitivity to how people respond to serious illness contributed to managing the two interviews in which participants became upset (Layla and Ellie, discussed in section 4.7, above).

The lack of a clinical background was a hindrance in the recruitment process, where a clear identity as a clinician or a student with a medical or nursing background would have provided a short cut to establishing trust with hospital staff. Some staff were keen to protect their patients from what they saw as a potential invasion of their privacy. Evidence of ethical approval for the study was requested by one member of staff, and after its production (via a phone conversation between this staff member and the ethics board), the staff member made the decision that she could not help. Claims to previous research experience could not be substantiated without lengthy phone calls or further paperwork, and there was little time to offer such evidence. In recruitment meetings where the PhD supervisor attended, staff accepted the student's credibility without question. In retrospect, wearing a medical school lanyard (rather than a small badge) may have conferred an aura of credibility when making recruitment arrangements, as hospital staff wore lanyards.

This clear outsider or lay identity had the opposite effect with patients, helping to establish trust. Some interviewees asked the student for her personal reasons for studying experiences of cancer. The information that long experience of the treatment

of a close family member for colorectal cancer had motivated “doing something useful” for other people in similar circumstances was volunteered; this seemed to reassure them that a level of sensitivity could be offered in talking about their illness. The student had the appearance of a conventional white, middle-class woman. All participants passed on during recruitment were white, and their residential postcodes suggested that recruitment spread across a range of levels of affluence.

For interviews the student dressed reasonably smartly but informally. Interviewees were all welcoming. The student’s age (fifty) seemed to lend a level of comfort to building rapport with participants, most of whom were older. One interviewee asked the student for her age, and the response satisfied her that this level of “life experience” would allow her to talk openly during the interview. Where the student was greeted at an interviewee’s door by a dog or a cat, this was clearly communicated as a source of enjoyment (Mark’s dog spent much of the interview hopping between the student and the participant’s lap). This encouraged rapport and perhaps encouraged participants to talk about their pets – although all participants with pets had included them in their photographic images.

4.8.1 The student’s assumptions about participants’ experiences

As someone who had observed the effects of cancer treatment on a close relative, but had not experienced it first hand, the student expected to interview people who might be feeling unwell or upset, or were having difficulties coping. Participants had been diagnosed at an early stage, and their level of equanimity in the face of their treatment was a surprise; cancer seemed to have had less of an impact on many of them than anticipated. The study’s research questions led to a focus on assets for coping, and participants offered many. The combination of these issues might have led to a bias towards the positive in the analysis – a conscious effort had to be made to investigate counterpoints in the data. The more difficult experiences of Janet and George, in particular, were considered carefully, to suggest ways of reworking these issues. This reworking contributed to the creation of the theme *Feeling isolated* (section 8.2.5) at a late stage in the analysis, and to further counterpoints in the data – for example, the

interpretation of the difficulties that some participants experienced in *Making plans* for the future (section 9.3.1.4).

4.9 Chapter summary

This chapter has considered the methodological debates surrounding research design. It has examined how we construe knowledge or “truth”, and the importance of stating a position on this at the outset of a research project. This project is situated within a social constructionist paradigm, which views knowledge and meaning as phenomena that we construct during our social interactions, and as something that is embedded in time, place and culture. From this standpoint, the study will investigate how people make meanings from their experience of cancer, and how these meanings might be mediated by the social and physical environments around them. Further discussion has considered the ethical and reflexive issues that arose during the course of the study, both in the context of interviewing participants who had been unwell and the use of the photographic images that they produced. The intention of this chapter has been to set the scene for the detailed presentation of data collection and analysis in Chapter 5.

Chapter 5: Methods – Data collection and analysis

...our research processes and assumptions need enhanced capacities to grasp and interpret the complexities and heterogeneities of social life empirically.

Adele E. Clarke, 2005^(234, pxxvi)

5.1 Introduction

This chapter begins by describing the experience of data collection, outlining interview procedures in detail and examining how photo elicitation was practised, in the moment. It also explores how participants responded to the photography task, and the lessons learned from this. The process of analysis is then described in detail, reflecting on the limitations imposed by issues arising during data collection. Challenges also arose in compiling a summary of photographic images in a way that made sense for the study, and in considering the role of the images in the analytic process and how to create an audit trail of their use. The chapter goes on to describe the use of situational analysis techniques to assist with this process, and how these procedures suggested novel sensitizing concepts that subsequently contributed to the analysis of the interview data.

5.2 Data collection

This section begins by describing the settings of the interviews. It then outlines first and second interview procedures in detail, describing the process of photo elicitation in practice and how participants responded to the use of this research method.

5.2.1 The setting

All interviews were carried out in participants' homes, with the exception of one, colorectal participant Layla, who asked to be interviewed in her workplace (a large sales warehouse – with her employer's permission, Layla chose a quiet seating area where the interview was not disturbed). In three cases, family members actively

wished to take part in the interviews, and where interviewees did not object, this was accepted without further question. Greg (PC) and Derek (CC) were interviewed with their wives present, who interjected occasionally (Derek was hard of hearing). Will's wife and daughter were present and took a larger part in the interview; all interview questions were directed at Will. It was not the intention of the study to investigate dyadic or group dynamics – it is acknowledged that this also requires a different approach to analysis⁽²⁵⁸⁾. There are occasional quotations in the findings that include a third party, where their statements elucidate or build on participants' statements.

5.2.2 The methods: semi-structured interviews and photo elicitation

Topic guides were developed to focus the interviews on the aims of the research (Appendices 5 and 6). The opportunity to pilot test an interview with a patient could have only been arranged via the same channels as recruitment. Data from the interview with the first participant was included as part of the study rather than treated as a pilot, but deliberately reflected upon to look for ways of improving the initial topic guide and photo elicitation technique.

Digital cameras were chosen to facilitate photo elicitation. This enabled participants to review the images they had recorded, delete images they retrospectively felt uncomfortable about sharing, and potentially further think about their reasons for including an image prior to the research interview(s). The distribution and retrieval of cameras in a way that protected confidentiality was labour intensive – the decision was made not to exchange any photographs through electronic means. Cameras were dropped off with participants by hand, and picked up by hand three hours or more prior to interview so that photographs could be printed out for use in the interview.

Participants were restricted to the two weeks prior to interview to take photos; the timepoint after treatment when photos were taken varied between participants in the same way as the interviews. This did not allow consistency of approach across participants, and did not accommodate taking photographs of everything that was significant during recovery. The brief did not require any record of progress in recovery (although some participants did offer linking photographs that demonstrated

progress). This approach was taken with the intention of not overburdening participants – there was no wish to make them feel that they had to produce a photo-documentary of their cancer experience.

In the interviews, participants were asked to decide the order in which to consider images, allowing them greater control of the agenda than in a conventional semi-structured interview. They were asked to explain why they took each photograph, and how it was significant to their experience of cancer. Before ending the interview, the researcher checked that dialogue around the photographs had led to the discussion of all topic areas in the interview guide. Where there were gaps, these were addressed in further questions and follow-up probes. (Most questions were covered by probes during dialogue about the photographs.) After the initial interviews it became clear that a topic guide laid out in a circular hub-and-spoke arrangement (rather than in linear fashion) would allow greater flexibility in responding to the participants' use of their photographs (Appendix 5). This enabled movement from one subject to another in the order that emerged in the photographs.

Longitudinal interviews were carried out with seventeen participants (see Table 3, column 1, p75). Timing second interviews at six months beyond each first interview proved challenging for reasons explored in section 5.4.2, below. Reasons for non-participation at this stage included one death among the prostate cancer participants (cause not known), an inability to arrange a convenient date for second interview with three participants, an inability to identify one participant via his GP surgery (a protocol required by the ethics board before second interview), and three participants being too close to first interview when the data collection period had to be closed. One participant withdrew because they were feeling unwell.

All interviews were audio recorded and transcribed in full. First interviews ranged from 39 minutes to 2 hours and 28 minutes long (on average, 1 hour 18 minutes); second interviews ranged from 24 minutes to 1 hour and 36 minutes long (on average, 57 minutes). The data and coding framework were managed using QSR NVivo 10. To minimise the burden on participants, transcripts were not sent to them for checking. With participants who undertook second interviews, themes from the first interviews were summarised briefly at the outset as an opportunity to check understanding.

5.3 How the participants responded to photography

A quotation from the first interview (with Lesley, 43/BC), illustrates how participant-generated photography works to capture not only a record of significant people, places and material objects, but provokes a level of interpretation from participants that goes beyond the immediately visible content of an image:

I was thinking, ah, you know, be nice to have a photo of [city], the place where I was like, "Oh, I've got me [biopsy] results coming!"...I would've been taking photos of the places, but really it's not the places, is it? Cos you could be anywhere, but – yeah – it's spending quality time with family.

At the end of the interviews, all of the participants who took part in photography were asked to describe their experiences of the technique. This section explores their responses, and considers lessons learned during the study about the practice of photo elicitation interviewing.

Participants were given a choice about whether they wished to take photographs. Table 4 (opposite) shows which participants chose to take part in photography: twenty participants (aged 40-81) took photographs prior to their first interview, and six (aged 75-84) preferred not to. Four stated that they didn't feel it was a necessary task – that they would find it easy to talk without photographs as a prompt – and two refused because they did not consider themselves to be a visual or artistic kind of person (they felt photography would require this, despite reassurances to the contrary). This is how Stephen (84/PC) explained his resistance:

Well, it wasn't any opposition to photography and it wasn't any feeling of privacy or anything like that. It was difficult to see quite what I could photograph...you've heard this over-loquacious spiel I've just been delivering, and what would you photograph out of that lot? It's not easy is it?...I could photograph my daughter or give you a copy of a photograph of my daughter, but that wouldn't illustrate the fact that we have an unusually close relationship. [Interviewer: We would have gone on to talk about it, but in fact we talked about it anyway.] Well precisely, I mean if you talk to me, by God you talk to me. Or I talk to you!

Ptp name (age)	Number of photographs taken	
	1st interview	2nd interview
Breast cancer		
Lesley (43)	9	6
Maura (81)	X	No interview
Clare (55)	10	X
Gill (40)	22	X
Mary (70)	21	X
Laura (46)	6	X
Harriet (72)	6	9
Liz (48)	10	X
Eleanor (71)	8	6
Janet (70)	7	X
Prostate cancer		
Tony (69)	25	X
Pete (75)	27	No interview
Martin (72)	41	No interview
Stephen (84)	X	X
Jack (65)	11	X
Arthur (77)	18	21
Greg (78)	X	No interview
Colorectal cancer		
Derek (81)	18	X
Fiona (69)	23	X
Will (75)	X	X
Ellie (64)	17	X
Layla (44)	6	No interview
Mark (62)	16	No interview
James (75)	12	No interview
David (80)	X	No interview
George (82)	X	No interview

Table 4 Choices to participate in photography (with “X” denoting refusal), and number of photographs per interview.

Interviews with participants who didn’t take photographs were of a similar length (average 1 hour 14 minutes) to the photo elicitation interviews (average 1 hour 18 minutes), and covered the same areas with the use of the same topic guide. There was a sense during analysis that the elicitation helped to deepen interpretation: sensitizing concepts that arose from the elicitation interviews – for example, stories displaying achievement and independence under the *Maintaining control* theme –

informed a search for the same or divergent themes in the interviews that did not use photo elicitation.

5.3.1 Participants' interpretations of the photographic brief

The majority of participants demonstrated a grasp of the ideas explained in the study's photography brief (Appendix 4) – that photographs should focus on subjects or items significant to their experience of cancer. Four participants talked about a desire to take the “right” kind of photographs for the research – they wanted to provide images that would do “whatever it is that you need” (Eleanor, 71/BC).

Most participants displayed an awareness of the kind of photographs that might “interest” a researcher (Pete, 75/PC) – for example, taking photographs of the wigs when hair loss was experienced through chemotherapy, of healthy food and healthy behaviours, of family, and of significant places. Mark (62/CC), whose photographs consisted of sixteen photographs of his dog (his most meaningful companion throughout his illness), talked about deliberately subverting the brief. He articulated his grasp of, and resistance to, the methodology:

The thing with it is I, I'm not taking photographs of cupboards and stuff like that, so I thought...if it, it might encourage somebody to get a dog...you have to go out, you have to, even if you don't feel like going out you've still got to take 'em out for a walk. So it makes, it makes you more energetic...I just thought it'd be more interesting for people who han't had a dog or have had a dog before and then found out that they're ill, it, I mean you've got something to play with, you've got something to do, han't yer? I mean you can take as many photos of a washing machine as yer like but it's still a washing machine, in't it [laughter], at the end of the day?

Participants were asked to take about ten photographs, but were advised that if they wished to take less or more this would be perfectly acceptable. Previous photo elicitation studies have limited the number of potential images by using 27-exposure disposable cameras^(247, 259). This study used digital cameras – the figure ten was given as a guide to allow flexibility without overburdening participants, based on previous

studies working with between seven and eighteen images per interview^(246, 251, 257). The low number of photos suggested encouraged some participants to think carefully about potential symbolism in their photographic images, and many participants were highly selective in what they chose to represent (Laura presented six images, Janet five). Others took many photographs, repeating similar content from multiple viewpoints, as many of us conventionally do when we go on holiday (for example, Tony and Fiona). Pete took multiple photographs of a holiday to represent one issue: that he had lived like a “hermit” and his treatment made him feel that he should stick his head “above the parapet” more, and spend more time with his daughter and her family.

A total of 323 photographs were taken for the first interviews, the number for each participant ranging from six to forty-one (see Table 4, p85). These totals do not include thirteen additional accidental photographs, for example of the floor, or thirty photographs that were identical repeats. Breast cancer participants for this study produce an average of ten photographs per interview (ranging from six to twenty-one), colorectal cancer participants an average of fifteen (ranging from six to twenty-three), and prostate cancer participants an average of twenty-four (ranging from eleven to forty-one). Breast cancer participants stayed closest to the brief – seven of them taking ten photographs or less. These participants selected what they wished to photograph carefully, and included fewer repeat images than other participants.

Eight participants (4BC/2PC/2CC) took the extra interpretative step of presenting photographs that they defined as significant because of their symbolism rather than their literal content. For example, a picture of holding hands was used to represent love, constancy and support (“We’ll hold hands [and photograph them]...I bet nobody’s ever done that”, Derek, 81/CC), and pictures of a clock (Eleanor, 71/BC) and a food timer (Harriet, 72/BC) to symbolise temporal aspects of experience. Janet (70/BC) took a picture of a tumble of unironed clothes to represent the chaos imposed on daily life by cancer treatment, and Jack (65/PC) photographed two sequential photographs of the building of a garden path as an allegory for his physical recovery.

5.3.1.1 *The question of “voice”*

Tinkler⁽²⁵⁶⁾ critiques the claim that photo elicitation hands the agenda of the research to the participant, suggesting that it is sometimes difficult to clarify whose story is being told. There is always a possibility that other people become involved in taking the photographs. In this project, of the twenty participants who took part in photo elicitation, thirteen chose to take all of their own photographs, and did not appear in the images themselves. Only Pete (75/PC) made the decision to take a self-portrait, holding the camera himself.

In the tenth interview for the study, with Derek (81/CC), it was clear that participant photography, including decisions about what to include in the images, was a joint enterprise between Derek and his wife. Derek’s eyesight and mobility were compromised by his stroke and other chronic health issues, which affected his capabilities with a camera; he was also a gregarious character, happy to share the task, and reported being taken by surprise when his neighbour used the camera to photograph him during one of their chats. Mary (70/BC), Fiona (69/CC), Layla (44/CC), Tony (69/PC) and Martin (72/PC) handed the camera to a family member to record their own presence in some of their images. The elicitation of participants’ own interpretations of photographs is the only way to assess their level of involvement in the task⁽²⁵⁶⁾. While there was no way to verify their control over the photography, all of the participants spoke about their images in a way which implied that they had remained under their direction.

5.3.1.2 *Lessons learned: managing a large number of images in a single interview*

All participants focused on the brief, but those who took more than seventeen photos included repeat images or several photographs containing almost identical subject matter. For example, Martin (72/PC) took twelve photographs of his dog and six photographs of family meals, and his remaining photographs were individual images. Pete (75/PC) took twenty photographs of the same family holiday, and seven individual images with different content. Where a participant presented more than ten photographs, this created a dilemma at the point of interview over how to be inclusive in covering the images that participants had taken time to represent.

In photo elicitation interviews, participants are often restricted to talking through a small selection of their images in the course of a time-limited interview (for example, five or ten photographs). The PhD student had recent previous experience as a participant in a photo elicitation study, with no limitation set for the number of photographs taken, and had been dismayed at the point of interview that dialogue would be restricted to five images. As a result of this experience, it was felt that asking participants how they wished to approach the task, given the time they had available for interview, would be less directive. Interviews using a large number of images provided an opportunity to experiment with this strategy.

In this study, all photographs were left open to interview dialogue, and where more than ten images were presented, participants either chose to talk through images in order of personal significance, or to group the images into similar subject areas (for example, photographs of the same person, object, place or activity). This led to a wide variation in the time spent talking about each photograph, depending on its significance or on the range of the narratives attached to the image. In studies where participants are asked to be selective about which images they talk about, while the researcher retains all of the images provided, there is a danger that assumptions might be made about photographs not discussed in the interview. This raises ethical questions about whether participants' photographs should be included in the analysis if the participant is not given an opportunity to explain their significance.

Twelve of the twenty participants who took photographs provided more than the requested ten images (2BC/5CC/5PC). Where multiple photographs of the same scene were presented, at times interview dialogue strayed from the research agenda. Some interviews had to be deliberately rescued from such tangents – usually by gathering together photographs that elicited the same narrative. Where this occurred, the PhD student asked whether additional photographs accurately represented a narrative already told, and if there was anything to add. These images were then set aside, and the interview moved on to the next image or set of images.

For example, Martin took the highest number of photographs: we looked at forty-one images in an interview lasting an hour and a half. At the outset of the interview, Martin was asked to group his photographs into rough categories, and we began talking

through them as he did this – he encompassed all forty-one photographs within a much smaller range of narratives with ease, linking them to narratives about his family, the local community and familiar haunts in his local environment. Tony’s interview considered twenty-five photographs. Nine of the images repeated scenes already photographed from a different angle – these nine images were condensed by Tony into three narratives corresponding with his bond with his grandson, his support for his son’s family, and the significance of the garden pond as a place of contemplation. All nine images were clearly linked with an overarching narrative exploring the significance of family connections.

5.3.1.3 Lessons learned: managing the interview topic guide alongside photographic images

The first three interviews for this study provided an opportunity to compare the shape of the photo elicitation interviews (Lesley and Clare) with an interview that aimed to cover the same topic areas without photographs (Maura). A conventional topic guide with questions printed in a list was used as a prompt for all three interviews. The intention was to begin photo elicitation interviews by talking through treatment experiences in order to build rapport, to move on to the photographs, and finally, to check through the interview topic guide for any subject areas not covered by the photographs, and ask further questions to fill in these gaps.

The linear topic guide provided good topic prompts in an orderly way for interview two (no photography), but it became clear that in photo elicitation interviews, the linear format encouraged us to return, piecemeal, to broad subject areas already covered in photographs in order to elicit further detail at the end of the interview. As discussed in section 5.2.2, the decision was made to rearrange the questions in the topic guide in a hub-and-spoke arrangement for elicitation interviews, with the photographs positioned in the centre and subject areas leading off in spokes (one per topic) in a circle around the photographs (Appendix 5). This arrangement of the topic guide was easier to work with in-the-moment, during interviews. Topic “spokes” were approached in the order in which they arose in participants’ photographs, with any supplementary questions asked while the topic was “live” in the context of looking

through connected images. Topic “spokes” not introduced by images were returned to at the end of the interview.

5.3.2 Photography for the second interviews

At the first of the second interviews, with Lesley (BC/43), before switching on the audio recorder, talk turned to the difficulties of taking photographs for the second interview, and that the photographic process had felt more self-conscious and less meaningful second time around, given that the participant’s story had already been partly told. Harriet (72/BC) also raised this in her first interview, concerned about taking photographs a second time:

[The photography] was more about, you know, the things that mean something to me, and I think I’ve almost covered them. Yeah. But you want more photos, Alison, and I [laughter] can’t think what I’m going to take...Really it’s not that much different from, at any other time, and had I, that’s how I would live my life anyway, you know – those things would have been equally as important before as they are now.

As a result of these conversations, the right to withdraw from photography was reiterated by the researcher at the point of organising each second interview. Only four participants elected to take a second round of photographs prior to interview (3BC/1PC). Of these four, during her second interview, Eleanor (71/BC) expressed feelings of discomfort at potentially taking too many photographs:

If I’d added any more I think I might have been pretending that...something mattered – finding something for the sake of finding something. These were the ones which sort of encapsulate – the ones that seemed the most sincere.

The literature on photographic methodologies outlines a concept worth exploring in relation to stories half told and the participants’ resistance to providing further images. Pink⁽²⁶⁰⁾ and Tinkler⁽²⁵⁶⁾ consider two levels of meaning attached to photographs used in qualitative interviews: meanings made at the point of production (the moment when the image was taken), and meanings made within the context of the interview.

Participants in this project had to think about the meaning of their cancer experience in order to choose what to photograph – what they wished to represent to a PhD student. In temporal terms, the act of representation during the first interview was close to the time of production (first interviews took place within two weeks of taking the photographs). First interviews were at a point when treatment was over, but still close in terms of time for most participants – the experience of cancer still felt novel, the shock of diagnosis still resonant in their accounts. In the second interviews, six months to one year later, participants had reflected further. Talk was not exclusively anchored around adaptation and recovery – it considered issues talked about in the first interviews in a new light. Clare (55/BC) articulated this in her second interview:

When I went through it, I seemed to be very positive and focused, but looking back, it kinda looks quite dark. Does that make sense?...that quite surprised me. And suddenly there was this like, "Oh actually, it was quite tough wasn't it?" [laughs] So retrospectively I can see [pause] yeah, it wasn't that easy. But going through it didn't seem that hard.

The job of documenting the experience in photographs, it seemed, had already been done at the point of the first interviews. The meanings made within the context of the first interviews were intimately associated with participants' images; the meanings made within the context of the second interviews included more reflection on how things had seemed when we had last spoken. Questions followed up strands of analytic thinking from the first interview data, and the topic guides for the second interviews included questions intended to drive towards theoretical saturation.

The photography brief had focused on social context. Participants were asked to think about their social, environmental and material resources (other people, places and objects) rather than embodiment issues, and did not take photographs of parts of their body in relation to their treatment. Arguably, the people, places and objects around them remained constant during the first year of recovery in a way that their bodies and symptoms did not. Harriet (72/BC) expressed this constancy, when asked what motivated her to take photographs for the project, using the present rather than the past tense: "It's just the things that I love and keep me going I suppose".

5.4 Analysing the interview data

There are a range of ways in which the data for this study could have been cross-cut for analysis – for example, by cancer type, by gender, by considering working age participants separately from retired participants, or by looking at longitudinal issues across first and second interviews (longitudinal analysis was an initial aim of the project). The primary aim of the project was to examine how social and material resources were used by participants in adaptation, focusing on commonalities and divergence across a broad range of people who had undergone potentially curative treatment.

Given the size of the sample, grouping participants into smaller categories for comparison would have drawn away from a focus on the more subtle differences between individual accounts. Where less frequent viewpoints were expressed, these are recorded in the findings where they seemed salient to the analysis. This included differences in participants' accounts that emerged within or between purposive categories such as cancer type and gender. A note was kept of the frequency with which themes arose among participants, and an indication of the number of participants contributing to themes is included in the findings. The longitudinal nature of the data was weaker than anticipated – constraints on the timing of second interviews were imposed by the slow pace of recruitment and the time-limited PhD framework. However, this produced some benefits for the analysis, which are described in section 5.4.2, below.

5.4.1 Interview coding procedures

Data was primarily coded by the PhD student. Secondary coding of six initial transcripts was carried out by an experienced senior researcher with a clinical background.

Codes were discussed across two meetings, with the transcripts to hand. The coding framework was taken forward and developed by the student (the final framework is shown in Figure 7, p97). Analysis progressed alongside interviewing. As new themes arose in interview data, they were pursued in further interviews to achieve theoretical saturation. For example, the concept of survivorship arose spontaneously in interview one, and was deliberately addressed and developed in subsequent interviews. Second

interviews provided an opportunity to follow up strands of analysis from the first interviews that seemed incomplete (this is described more fully in section 5.2.8, below). The analytic techniques used to interrogate the data are described below.

Grounded theory: Initial analysis used Charmaz's⁽²³⁵⁾ technique of open coding using gerunds ("ing" words, or verbs), to keep action and process central. Memo writing began at this stage and continued throughout the analysis to assist the development of substantive codes from initial categories and concepts. At all stages, codes were laid out visually to identify patterns and overarching concepts – an iterative process of axial coding that continued until the theoretical framework was fully developed.

Situational analysis: A social worlds map was constructed to conceptualise the key areas of action in and around the survivorship arena (Figure 5, p95) and inform the ongoing development of coding. An ordered situational map was drawn up after the initial twelve transcripts had been open coded (Figure 6, p96). This could have been carried out prior to interview to elucidate areas for discussion, but the decision was made to develop concepts for the map from the interviews. This helped to exploit the study's single source of data as fully as possible, staying close to the participants' agendas and developing concepts from the bottom up rather than working in the context of *a priori* concerns. It is to be noted that the map in Figure 6 suggests new lines of research enquiry that could be followed up using different data, as much as representing issues arising from the interviews gathered for this study. Positional maps were created to elucidate counterpoints in the data, and situational maps to draw overarching concepts together (see section 5.5 for a worked example of situational mapping).

The role of photo elicitation: Participant photography was initially intended as a data collection tool – the analysis was led by the verbal interview data. A later decision to use the photographs to assist in a specific section of the analysis is discussed in detail in section 5.5.

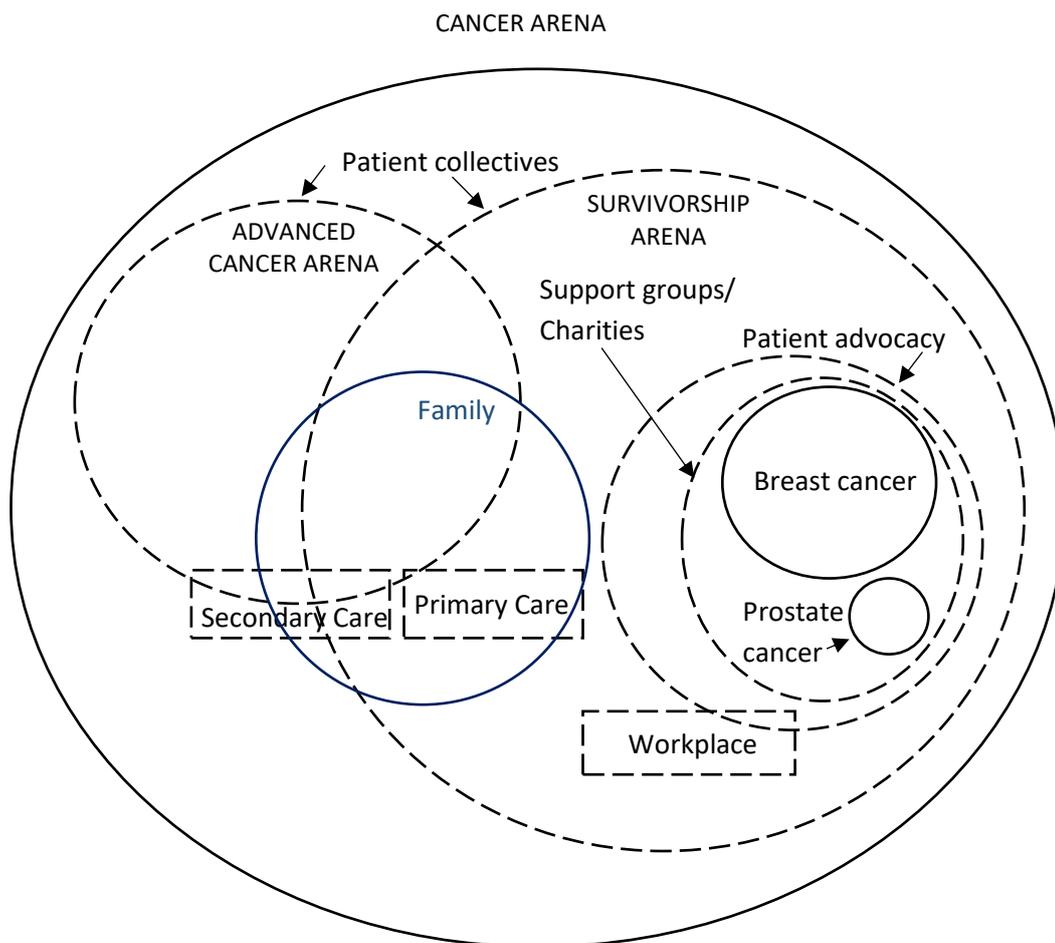


Figure 5 A social worlds/arenas map. In situational analysis, mapping interprets broad relationships within the situation under focus. This map interprets the potential crossover of worlds in participants' lives, with dashed lines representing fluid boundaries. Institutions are shown in rectangles. The social worlds of family, workplace and the patient collective, which appear in the coding framework, are represented.

<p>Individual human elements/actors Person with cancer Spouses/partners/children/parents Family members with cancer history Friends with cancer history Family members with no cancer history Friends with no cancer history Acquaintances with cancer Doctors/Specialist Nurses/GPs Outpatient volunteer staff</p> <p>Collective human elements/actors Survivors (by cancer type) Family Secondary care/Primary care Employers/Work colleagues Charities; social media; other media “Community”?/Local service providers</p> <p>Discursive constructions of human actors Cancer is a death sentence Cancer is payback You must take treatment The worst case scenario I don’t want sympathy Invisible cancer is still cancer Narratives about fairness (Why me? Why not me?) Recovery as luck Illness as fraudulent The wrong thing to say Who I am What illness makes you What “normality” is The supportive family The supportive friend The good patient The good survivor</p> <p>Political elements Survivorship advocacy Perceptions of cancer charity discourses Perceptions of NHS capacity Responsibility to be a good patient Responsibility to be a good survivor</p> <p>Economic elements Effects on work/resources Active management of finances Selective deafness of financial institutions Effects of pension on present comfort Generational differences</p>	<p>Temporal elements Trajectory of care Trajectory and pace of recovery Family histories and your place within them</p> <p>Major issues/debates that are usually contested What causes cancer Other people’s attitudes towards cancer Survivorship as a craft What to say to people with cancer Whether to display patient status</p> <p>Other kinds of elements Stage of cancer; age at diagnosis; residential location (urban/rural); level/quality of social support; management of emotions</p> <p>Nonhuman elements/actants Radiotherapy machines Pharmaceutical treatments Immediate environment and its effect on mood Physical expectations in line with employment</p> <p>Implicated/silent actors/actants Absent family and friends; acquaintances; surgeons; charities; GP Practices; the NHS</p> <p>Discursive construction of nonhuman actants Treatment in this town is top class Must be prepared for the worst case scenario, regardless of details of diagnosis</p> <p>Sociocultural/symbolic elements Gender – differences expected or lived up to; sexuality – who it matters to (patient or spouse); age; affluence; the reputation of cancer; expectations of employers and colleagues</p> <p>Spatial elements The home: availability of domestic resources Rural v urban: travel to treatment Confidence in using public transport Living locations of family Nearness to facilities (e.g. mobile library)</p> <p>Related discourses (historical, narrative, visual) The survivor narrative Recovery narratives Patient autonomy Patient responsibility Cancer through family generations</p>
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Figure 6 *Ordered situational map.*

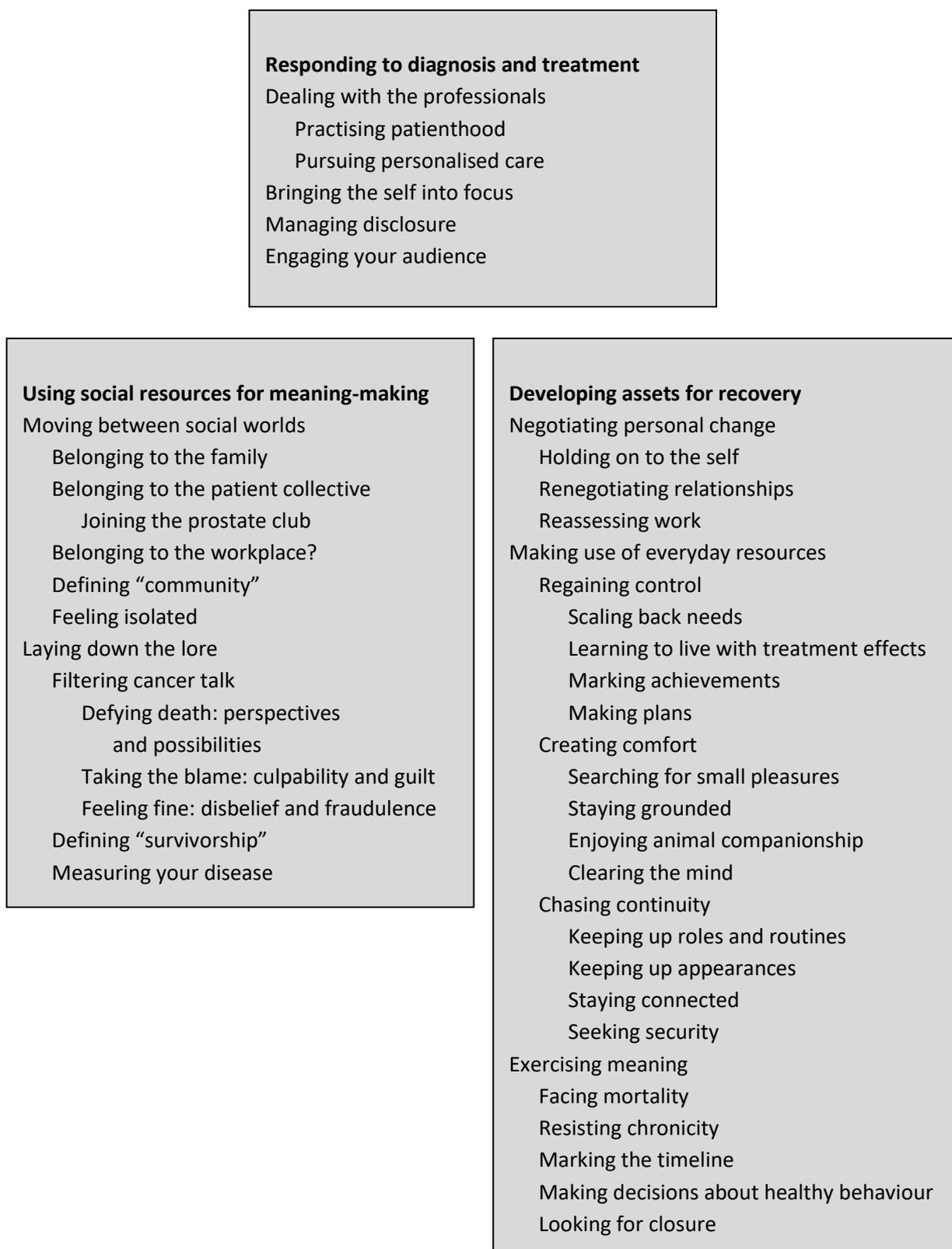


Figure 7 *The coding framework.*

5.4.2 Limitations imposed on the analysis by data collection procedures

The initial intention, at the beginning of analysis, was to separate data from the first and second interviews to give a longitudinal picture of two timepoints, and to look at how adaptation progressed between these times. Meeting with participants at specific timepoints proved difficult: recruitment was slow, across a period of twelve months. Once participation had been secured, arranging convenient times for patients for their first interview took between one and three months. Allowing time for participant photography added a minimum of two weeks to the timescale prior to interview.

Participation was voluntary, and interviews were carried out at dates suggested by the participants – while contact could be made at the appropriate time by the researcher, this did not always result in an interview at the preferred timepoint. As a result, methods of recruitment did not guarantee participation at a standard timepoint. First interview timepoints ranged from six weeks to nine months beyond treatment, at an average of five months. For the seventeen participants who participated in a second interview, second interview timepoints ranged between ten and eighteen months beyond treatment, at an average of thirteen months.

The variations in timepoints across participants was reflected in the data. As analysis of the first interviews came to a close, it became clear that the emerging themes reflected unfinished stories for many participants, who were still in the midst of making sense of their experience of cancer, alongside more developed stories of adaptation from those who were interviewed further through their cancer experience. It became clear by the close of analysis on the first interviews that themes taking into account issues beyond the immediate aftermath of treatment would not be fully explained until the second interviews were complete. Longitudinal issues were weakly represented in second interview data. Considering all forty-three interviews as a whole, representing the findings as a three-stage sequence seemed a better fit for the data set. In the findings, the three stages have been summarised under the following headings: (1) responding to diagnosis and treatment, (2) using social resources for meaning-making, and (3) developing assets for recovery.

5.5 Using the photographs in the analysis

Analysis of the photographs separately from the interview transcripts was not part of the protocol for this project. At the outset of the study, the images were intended to facilitate interview discussion, and to maintain a focus on external resources. The intention with the photographic material was simply to catalogue the images by participant (age/gender/cancer type) and subject matter. When data collection was complete, a decision was made to categorise the photographs using codes, following the method of compiling a dictionary of images suggested by Luttrell⁽²⁶¹⁾. It became clear during analysis that images of objects and places might contribute to answering the research question focusing on how people make use of their everyday resources. In combination with the visual approach to data exploration suggested by situational analysis^(234, 242), this led to a decision to map out the material objects and settings shown in the photographs to see whether data directly connected with the images might be pulled together into conceptual categories. Section 5.5.2 outlines how the content of these images connected with three concepts which were then explored using the interview data – control, comfort and continuity. These are described in detail in section 9.3 of the findings, *Making use of everyday resources*.

5.5.1 Compiling an image dictionary

Experimentation with coding proved that the creation of a set of descriptive categories for the images was possible – for example, relationships (photographs of other people), self, settings, and content such as transport, medication and activities. However, mutually exclusive categorisations, as recommended by Luttrell⁽²⁶¹⁾, would allow little room for insight into how the images taken for this study related to the themes within the data. For example, social interaction is a key focus in the analysis, and the category of photographs with the highest number of images was “Relationships”, but a selection of images containing family and friends also represented activities or food and drink. Consequently, rather than aiming for mutually exclusive categorisations, images were grouped in relation to some of the thematic strands arising from the social, material and environmental issues that emerged in participants’ accounts.

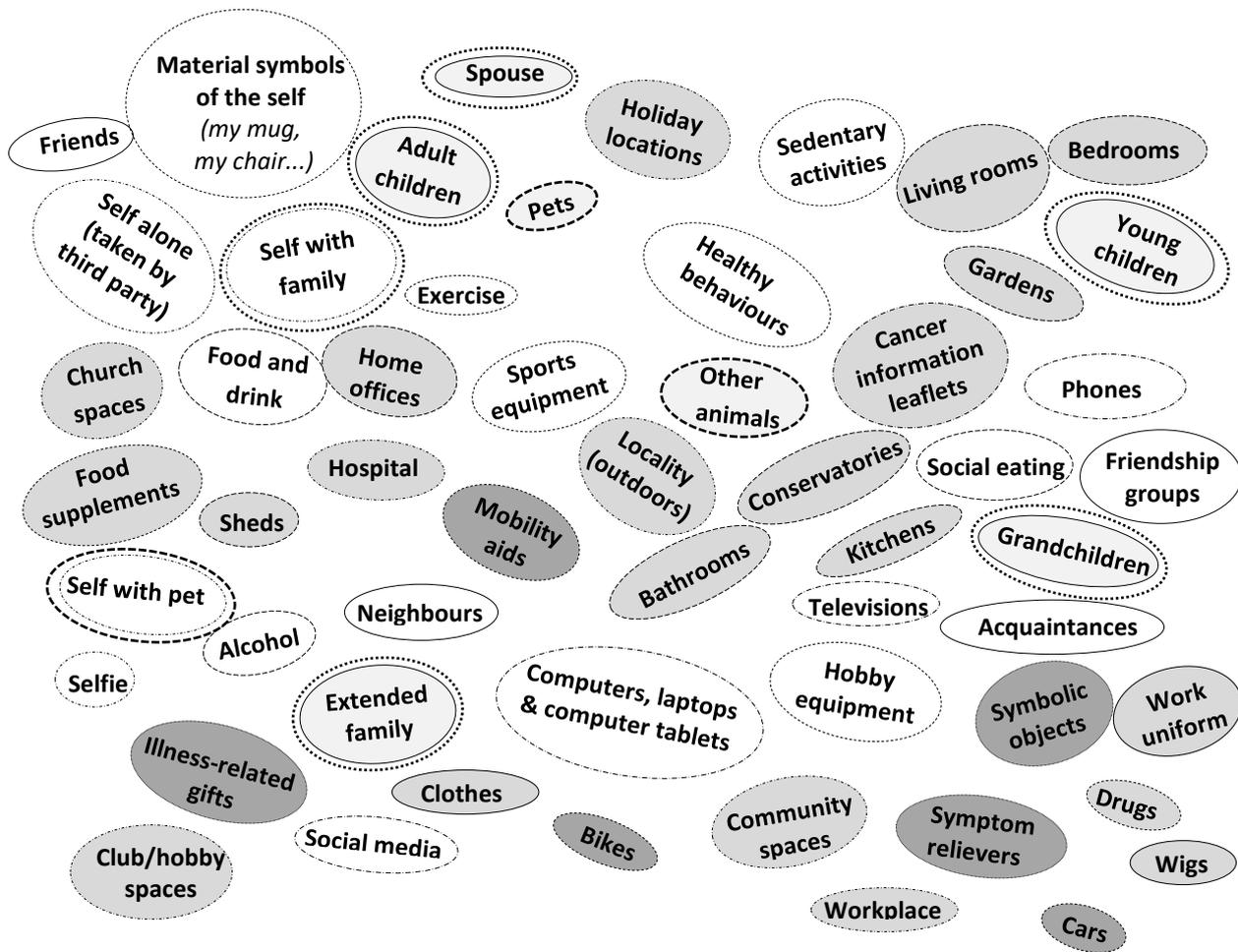
Situational analysis techniques were used to examine the content of the photographic images. A simplistic “messy” map⁽²³⁴⁾ was constructed of the main visual content of the photographs (see Figure 8, opposite), and categories were drawn together by linking different aspects of the contents in a relational map (see Figure 9, p102). Table 5 (p103) shows a breakdown of the participants’ images by coding category. These figures must be contextualised with some firm caveats.

From looking at the frequency of images within the categories in Table 5, we might draw the conclusion that relationships – family, more than friends – were a key resource; we might also conclude that pets are highly significant to people when they are recovering from treatment. We cannot infer further significance beyond these broad assumptions. We might also infer that physical appearance was more significant to breast cancer patients than to prostate and colorectal cancer patients. These inferences may provide clues to follow-up in the data; in this study, they arose as clearly in the verbal data alone. Interview data confirmed that family support was more salient than friendship support, and that changes in appearance were most salient to breast cancer participants (they had undergone chemotherapy and experienced hair loss and changes in body shape as a consequence of surgery – prostate and colorectal cancer patients did not report the same experiences).

The frequencies of images in these coded categories cannot tell us more than the data attached to them in the interviews – they tell us less. This is not surprising given the practicalities of the task – for example, having to focus on the places and experiences that happened to arise in their life within the two weeks given for photography, and the range of potential interpretations of the brief. Participants were not asked to be researchers – to work to a specific rule or have rule-breaking images dropped. The approach was inclusive, informal, and as boundary-free as possible, to give room for participants to set their own agenda within the framework of the research focus.



Figure 8 *Messy map of photographic image categories.*



KEY:

Relationships	Family	Animals	Activities	Self	Food and drink	Technology
Physical appearance	Objects	Transport/Mobility	Medication	Information	Setting: Domestic	Settings: Other

Figure 9 Relational map of image categories – a representation of a hand-drawn map in which categories were ringed and joined up with lines.

Category	Number of photographs	
	Interview 1	Interview 2
Relationships:		
Family	62	3
Friends	6	2
Pets/Animals	57	0
Activities:		
Sedentary	14	2
Active	25	2
Sports equipment	7	2
Self (taken by a third party)	36	0
Food and drink, including social eating	26	0
Technology (computers, TVs, phones, social media)	19	0
Physical appearance (clothes, wigs, face)	10 (8BC/1PC/ 1CC)	1 (BC)
Significant domestic objects:		
Associated with symptom relief	8	2
Symbols of the self (my mug, my chair, my perfumes, my artwork...)	7	1
Illness-related gifts	5	0
Transport/Mobility	5	0
Medication	2	0
Cancer-related information (leaflets)	2	0
Breakdown by setting:		
Domestic spaces	112	5
Community spaces	33	0
Local environment (outdoors)	17	1
Club/hobby venues (e.g. puppy training, art class)	13	5
Churches	6	0
Hospital	5	0
Holiday locations	27	6
Workplace	2	2

Table 5 *Breakdown of the participants' photographic images by category.*

5.5.2 Exploring control, comfort and continuity

Further relational mapping was carried out using the content of both individual images and a selection of relevant categories drawn from the image dictionary. The resulting visual provided a basis for revisiting the associated interview data, and the examination of three concepts linked to the images: control, comfort and continuity. This visual was too extensive and untidy to reproduce effectively – Figure 10 (opposite) summarises the associations between images and themes in a more accessible way.

5.5.3 Reflections on the inclusion of photographic images in qualitative analysis

The issue of how to analyse participant-generated photography as part of social research projects, or whether to analyse them at all, is a contentious one. Photographs generated by participants when the researcher is not present are often marginalised or ignored in texts concerning visual methods – for example, Banks and Zeitlyn⁽²⁶²⁾ focus on researcher-produced and researcher-assisted photography. The reification of photographic images above the verbal interview data connected with them justifies accounts of analysis that depend primarily upon the researcher's interpretation of photographs, rather than the participants'. For example, in Tinkler's⁽²⁵⁶⁾ "talk-focused" and "photo-focused" approaches to analysis, the first depends upon the researcher interpreting participants' images prior to interview, the second on equating the frequency with which specific content appears in images with its level of meaningfulness.

There are obvious limitations to these types of analysis (also considered by Tinkler): the marginalisation of content through the absence of potentially research-relevant images that have not been photographed, the lack of acknowledgement of links between photographs and their tone or mood (an issue explored in greater depth by Rose⁽²⁶³⁾) and the absence of the participant's interpretation of the images. Tinkler⁽²⁵⁶⁾ goes on to consider the contextualisation of photographs – how participants talk about images, and the material, cultural, social and physical factors that influence their choice of what to photograph.

<p>CONDITIONS (Which experiences provoke the need to gain control, comfort and continuity?): Experiencing loss – of physical capabilities/wellness, of social contact, of purpose, of ease. The need to position yourself along a continuum, so that you can see where you are going. The need to deal with treatment in the short term, while thinking about the longer term.</p>			
Theme/ Concept	<p>CONTROL Moving forwards <i>Temporal:</i> Short term (ST)-----Long term (LT)</p>	<p>COMFORT Alleviating loss of ease (psych/somatic) <i>On a continuum:</i> Dis-ease-----Ease</p>	<p>CONTINUITY Maintaining momentum in the face of disruption <i>On a continuum:</i> Maintainance-----Disruption</p>
Key associated processes	Scaling back needs (ST) Living with treatment effects (ST) Marking achievements (LT) Making plans (LT)	Searching for small pleasures Saying grounded Enjoying animal companionship Clearing the mind	Keeping up roles and routines Keeping up appearances Staying connected Seeking security
Associated phrases from the data	making progress – Jack being purposeful – Eleanor looking forward – Layla	my bit of luxury – Liz feeling at home – Harriet being miles away – James	trying to get on with things/look normal – Lesley knowing what’s happening – Arthur carrying on/not missing out – Jack
Examples of associated photographic images	Building a garden path Running medals Diaries Incontinence bottle Kitchen timer Holidays	My chair, my mug, my bedroom... Gardens Gifts Food Pets Local environment	Computers and computer tablets Hobbies Memorials Televisions Walks Social eating
<p>COUNTERPOINTS (What circumstances have the potential to disrupt efforts to gain control, comfort and continuity?): Hospital waiting times – Ongoing physical difficulties, including ageing – The expectations of others – Social isolation</p>			

Figure 10 How participants talked about their everyday resources: thematic mapping for the concepts of control, comfort and continuity, with examples of associated photographic images.

In this project, the photographs were not analysed prior to interview, and the participants' explanation of the images was privileged during the interview. Participants contextualised their own images, making links and explaining mood and tone where appropriate. A consideration of the limitations described above in relation to the methods for this study suggested that three questions could be usefully asked of a collection of participant-generated photographs: What is marginalised? What is idealised? What is missing? These questions will be briefly addressed, illustrated with examples from the data.

5.5.3.1 What is marginalised?

An image that occurred only once in the photographs, but arose several times in the interview data, is alcohol. Derek (81/CC) was the only participant to take a photograph of an alcoholic drink: a pint of Guinness. In his interview, Guinness was construed as beneficial to his health as an appetite stimulant. Photographs of food and drink were based around social eating and healthy foods, but interview talk about food and drink suggested that healthy foods were difficult to eat during treatment. Participants reported changes to their sense of taste during chemotherapy (Lesley, Gill), and difficulty consuming previously preferred foods such as mushrooms (Ellie), coffee (James) and alcohol (Jack, Mark) as a result of radiotherapy treatment. Recovery of the ability to consume preferred food and drink was pursued at the cost of unpleasant digestive symptoms. These issues arose in the interview data regardless of their lack of documentation in the photographs, and are considered in detail in the findings (section 9.4.4, *Making decisions about healthy behaviour*).

The importance of hospital acquaintances in the analysis of social worlds (outlined in the findings in *Belonging to the patient collective*, section 8.2.2) is undocumented in the photographs. Four participants provided photographs of the hospital where their treatment took place – Lesley took a view from a window during chemotherapy, Eleanor took a photograph of the path in and out of the unit as a metaphor for her treatment “journey”, Pete photographed the outside of the hospital building, and Arthur took two photographs related to the radiotherapy staff. The significance of the

radiotherapy department among the prostate cancer patients and of social interaction with other patients could not have been inferred from the visual data alone.

This was partly an artefact of ethical guidelines about confidentiality: participants were asked not to photograph other people without their consent, and many may have felt that photography would be an intrusion in a health care setting. It also reflected the timing of the photography task; participants were given a camera for just two weeks prior to interview, and if a hospital visit did not occur in that fortnight, there would be no opportunity to take a picture of the hospital. Leading the analysis with the verbal interview data, and an interview topic guide that considers a consistent range of subject areas alongside (and supplemented by) participants' images, helps to ensure that significant issues do not remain hidden behind ethical or practical concerns.

5.5.3.2 What is idealised?

The question of whether participants chose to take photographs that deliberately portrayed them in a positive light is difficult to answer without using interview data to explain their motivations. The use of digital cameras allowed participants the opportunity to delete images, editing their initial decisions. Discussion with participants about the photography at the close of the interview, and their inclusion of accidental and repeat photographs, suggested that this had not occurred. The point at which these issues can be addressed is within the interview situation itself, and relies upon the interviewer to sensitively probe about the production of the images.

Interview data for this study suggested that several participants possessed implicit knowledge about what kind of images might interest a researcher (see section 5.3.1). It is arguable whether lay knowledge of documentary photography, as it appears in newspapers and on social media, might lead to the construction of images to satisfy the imagined research agenda rather than a true representation of experience. A similar argument can be voiced in relation to the interview method – participants are as capable of providing a narrative that sets them in a particular light as they are of producing images that support a certain construction of the self.

In this study, an illustration of how this issue may affect interpretation arose from the difficulty in disentangling healthy activities from good intentions to explore the theme *Making decisions about healthy behaviour* (see the findings, section 9.4.4). For example, were Fiona's three photographs of herself doing yoga a deliberate attempt to construct an impression of good health behaviours? Her interview suggests that yoga had not been a regular part of her life to date, but was a relatively new hobby (which may or may not continue); Fiona was clearly motivated to be a good patient. Overall, the photographs included twenty-seven images of participants taking part in activities that required physical exercise, but the images in themselves told nothing about the duration or regularity of those activities in the months beyond treatment.

5.5.3.3 *What is missing?*

The twenty participants who took photographs were asked whether any crucial images were missing, thinking retrospectively at the end of their first interview ("Are there any photographs you feel you should have taken, but you didn't?"). Six participants described photo opportunities they felt they had not taken up. Five "missing" photos would have been of family members – of more distant family who gave support throughout treatment but were not present during the fortnight allotted to photography, and of family events which participants had intended to photograph but had become absorbed in the moment and had forgotten the presence of the research camera. The sixth and seventh "missing" photographs were suggested by Ellie (64/CC), who felt that she should have photographed her book and her bed to demonstrate the comfort they brought after surgery.

5.6 Chapter summary

The research design for this study demanded attention to social context from the outset, and the methods of photo elicitation and situational analysis were chosen to address this, alongside a core focus on constructivist grounded theory coding techniques as a rigorous way of examining individual experiences. This chapter has examined how semi-structured interviewing using photo elicitation worked in practice, and explored the lessons learned from this process. It also documents the process of

analysis, and how the photographic images produced by participants contributed to this in unexpected ways. Chapters 4 and 5 have outlined how the limitations imposed by the pace of recruitment shaped the outcome of the analysis: considering the role of unfinished stories and ongoing sense-making in the temporal structuring of the data sets the scene for the following chapters, which outline the findings of the study.

Chapter 6: Introduction to the findings

I've been equipped with this irrational optimism, in that I don't get ill.

Good heavens, apparently I am ill! [pause] Most people get better.

Well, I'm most people, you know.

Stephen (84/PC)

6.1 Introduction

This chapter outlines how participants' experience is represented in Chapters 7, 8 and 9, which explore the study findings. The majority of participants sensed that they belonged to a group of people with cancer who had been fortunate with the outcome of their treatment. They had completed treatment at the point of their first interview, but were still in the midst of making sense of the experience. This is where the findings begin. In first interviews, participants were keen to explain their diagnosis and how it made them feel, and how they responded to the changes that treatment had introduced into their day-to-day lives. As first interviews progressed, talk moved towards how others around them had reacted to their situation, and how their social interactions had offered them ways of framing their experience. This process of sense-making suggested to them ways of adjusting their thinking, their ways of relating, and their use of material resources to make and to measure their recovery. At the point of the second interviews, participants had become clearer about where to place their experience of cancer in the context of their lives. A broader picture of the sense-making process emerged, and the way that participants used their resources to facilitate adaptation came more fully into focus.

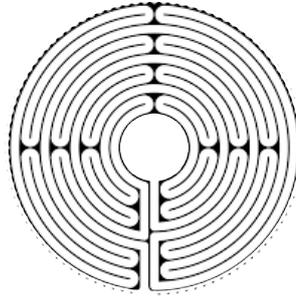
Throughout the findings chapters, each quotation from the data is labelled with the participant's name, and followed with an identifier denoting their age and cancer type – BC for breast cancer, PC for prostate cancer and CC for colorectal cancer. Where the frequency of appearance of a theme is denoted in the findings, the spread across cancer types is given in parentheses where it is informative – for example,

“2BC/4PC/2CC” would denote contributing data from two breast cancer patients, four prostate cancer patients and two colorectal cancer patients. Participants’ names have been replaced throughout by pseudonyms.

The following section outlines the structure of the findings. It begins by introducing an overarching metaphor drawn from the words of two of the participants, which seemed to resonate with the data as a whole: Tony (69/PC) and Eleanor (71/BC) represented their experiences of cancer as a curve in life’s pathway. This metaphor is reflected in Figure 12 (p114), which summarises the content of the findings chapters based on the final coding framework shown in Figure 7 (p97). This diagram outlines the social processes interpreted from the data; it also specifies the preconditions that set each process in motion. It does not represent a stage-model of adaptation – the social processes described in *Chapter 8: Using social resources for meaning-making* and *Chapter 9: Developing assets for recovery* combined to set life’s pathway straight in different ways for different participants.

6.2 Turning a curve: adapting to life after cancer treatment with curative intent

One metaphor stood out in the data as a useful mirror of participants’ experiences. Tony (69/PC) characterised the pathway of potentially curative treatment and recovery as a “steady curve”. He used this to describe reorienting to life after cancer at a controlled pace, contrasting it with the sudden “turn” that life might take when cancer is more aggressive or more difficult to treat. Eleanor (71/BC) echoed this steady curve in a second metaphor. Eleanor described her experience of the meditative activity of walking labyrinths – in her second interview she presented a photograph of the curving pathways of a labyrinth to represent life’s pathway (see Figure 11, opposite). Most of us experience times when the path is relatively straight, and the way ahead is visible. Cancer is a curve in the pathway, a deviation in our walk, a moment when the view ahead is suddenly not visible. It requires a change of pace to take the curve – to reorientate and carry on. Like the pathway in the labyrinth, most people’s life experiences contain more than one curve or deviation, and cancer may not be the most salient crisis in someone’s life.



“You can’t get lost in a labyrinth...it’s a metaphor for life really because you’re only on one path...there’s a start and an end...there may be [a] time when the twists and turns are very short. And then another time you go nearly all the way round before you go on to the next twist...that’s like life, as well.”

Figure 11 Eleanor’s labyrinth metaphor. Her photograph shows the bottom section of a labyrinth with curves in its pathway. A full diagram of a labyrinth is shown above the photograph. The quotation is an excerpt from her second interview.

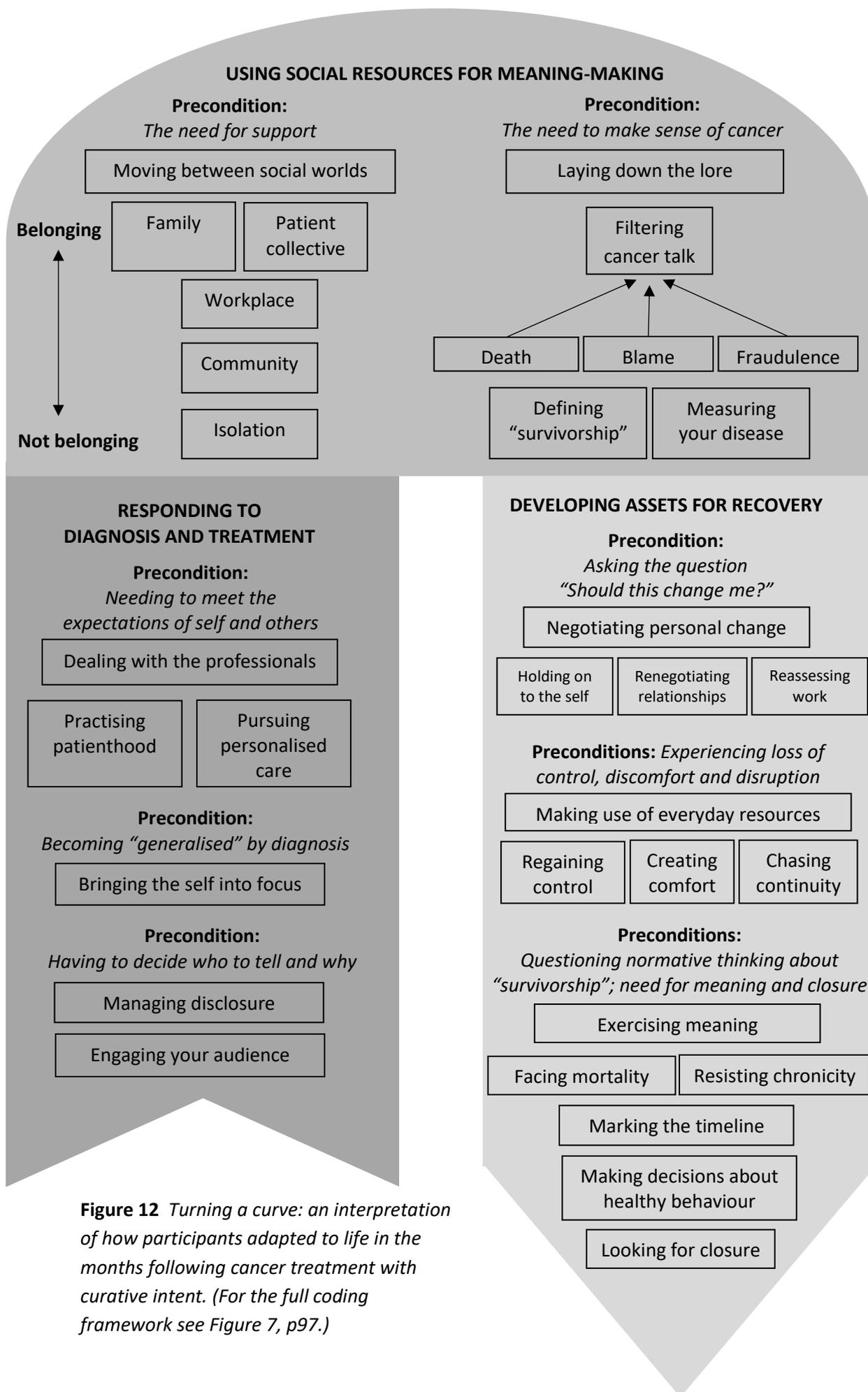


Figure 12 *Turning a curve: an interpretation of how participants adapted to life in the months following cancer treatment with curative intent. (For the full coding framework see Figure 7, p97.)*

As the curve approaches, preparations for a change of pace begin. This is represented in Chapter 7, *Responding to diagnosis and treatment*. This chapter explores the data from the beginning of the first interviews, which began by giving participants an opportunity to describe their diagnosis and treatment as a way of settling in to dialogue, to build rapport. They described listening to health care professionals explaining the new challenges and expectations that needed to be met (*Dealing with the professionals*). As treatment began, participants looked back to examine pathways they had already walked and how they had negotiated these, calling on previous experiences and proven capabilities to gather strength (*Bringing the self into focus*). Experiences of care that felt personalised supported this strengthening of the self. For all but two participants, cancer was a novel experience (James had experienced two other early cancers in his bladder and lung; Mary had previously been treated for a cancer in her leg). Making decisions about who should witness or accompany them through the cancer experience was not easy – *Managing disclosure* and *Engaging your audience* describe this process.

Chapter 8, *Using social resources for meaning making*, examines how participants used social interactions to make sense of their situation, and began to reorientate. This is represented in *Moving between social worlds* in terms of their movement between social groups. Drawing on Eleanor’s interview data, the labyrinth metaphor is extended in this section to explore how social groups fluctuate as people walk along different life pathways. Within participants’ social worlds, conversations with other people helped them to think about the social norms surrounding cancer, and decide which they wished to live up to and which they wished to resist. In this way, participants incorporated their cancer experience into their frameworks of meaning, *Laying down the lore* about cancer as they saw it.

Diagnosis separated participants from other people who were “carrying on with their lives” (Laura, 46/BC), and where social worlds were a source of support, their sense of belonging was reaffirmed. Participants had differential access to social worlds: the most significant source of support was the family unit (explored in *Belonging to the family*). Secondary sources were interactions with other patients in cancer clinics (*Belonging to the patient collective*), and for those who were employed, continuing

relationships with work colleagues (*Belonging to the workplace?*). Participants found it difficult to conceptualise wider community support – this is explored in *Defining “community”*. For a minority of older participants, cancer had left them *Feeling isolated* – the combined experience of cancer and ageing sensitised them to the narrowing of their social worlds.

Themes in Chapters 7 and 8 began with first interview data, and coding was refined with data from the second interviews. Coding for Chapter 9, *Developing assets for recovery*, drew on data from both first and second interviews to take an overview of the adaptation process. The majority of participants conceptualised this process as recovery (returning to life as it was before cancer) rather than adaptation (the adjustment of meanings and behaviours to accommodate the effects of treatment). *Negotiating personal change* focuses on the adjustments participants made within their social worlds – a tweaking of social resources – to accommodate their experience of illness. *Making use of everyday resources* considers ways of behaving that promoted recovery, and the role of material objects in this process. *Exercising meaning* explores the sense-making process that helped participants to orient themselves to the future, and how the marking of social events helped this orientation.

To return to Tony and Eleanor’s metaphor, cancer creates a curve in the pathway, temporarily removing a clear view of the future and throwing the past into greater relief. For patients who have been treated with curative intent, turning the curve happens at a steady pace. Social resources help to calibrate the turn, making it smooth or slow progress. The negotiation of new frameworks of meaning help the person with cancer to reorientate. Cancer is demanding, it creates expectations that are uncomfortable. Self care is an instinctual imperative, but cannot be achieved without effort. This effort can be eased by social support, and by harnessing everyday material resources in the domestic environment to create a sense of control, of comfort, and of continuity. Normative assumptions about “survivorship” are questioned by the participants in this study – meaning-making is a key process in defining cancer as chronic or acute, in making decisions about healthy behaviour, and in achieving a sense of closure.

6.3 Participant photography

Participant photography maintained a focus on contextual issues by helping participants to think about how other people and material objects had been significant to them during treatment and recovery. A small selection of representative images are used throughout Chapters 7 to 9 to illustrate the themes.

6.4 Chapter summary

This chapter has provided an overview of the study findings, which will be outlined in detail in Chapters 7, 8 and 9. It introduces cancer as a curve in life's pathway as an *in vivo* concept (derived directly from participants' words). The curve needs to be taken at a steady pace to allow participants to adapt or reorientate. The main social processes that comprise adaptation, from treatment into the months beyond, are interpreted using the themes mapped out in Figure 12 (p114), derived from the coding framework given in Figure 7 (p97).

Chapter 7: Responding to diagnosis and treatment

I didn't want sympathy...I've got two sisters...one of them sent me a card saying "Life is hard sometimes"...and I ripped it up...I can laugh about it now, but at the time I was really annoyed, thinking, I don't want your sympathy, I don't want your kind words!

Laura (46/BC), Interview 1

7.1 Introduction

In the first interviews, most participants began their stories of diagnosis and treatment by talking about the interactions with health care professionals that shaped their care. Diagnosis was described by the majority of participants as a shock – a moment in which they felt isolated. Within days, there were expectations to live up to – interactions with both professionals and lay people suggested ways in which they should behave. The first section of this chapter describes *Dealing with the professionals*, and examines how implicit prescriptions for behaviour were interpreted from conversations with doctors and nurses, and how the generalisation of patient experience in professional communication presented difficulties for participants. The second section, *Bringing the self into focus*, explores how comments made by other people impacted on participants' sense of identity. Experiencing conversations about their own cancer for the first time, participants realised that they could exercise choice in deciding who to inform about their illness. *Managing disclosure* describes how these choices were made, and *Engaging your audience* explores the ways in which disclosure could be managed in order to share the experience or maintain privacy.

7.2 Dealing with the professionals

In talking about diagnosis and treatment, participants described their interaction with oncologists, specialist nurses and GPs. Two clear perspectives emerged: *Practising patienthood* examines participants' experiences of living up to what's expected of them as a patient; *Pursuing personalised care* explores how generalised expectations

about cancer treatment were unhelpful, and which professional behaviours were successful in conveying an individualised approach to care.

7.2.1 Practising patienthood

In deciding how to behave as a cancer patient, participants found themselves caught between two counterpoints: the paternalistic expectation that they should behave in a way which pleased their doctor, alongside the responsibility to be an empowered patient and a critical consumer of care. Communications from professionals were interpreted as guidance about how to behave. Ideas about how patienthood should be performed varied across the cancer types and timepoints. For prostate patients, psychological rewards for good behaviour were focused on conforming with treatment protocols. For colorectal cancer patients, the sense of approbation received from professionals for completing surgery or radiotherapy was the most salient influence. Derek (81/CC) felt that his surgeon was “pleased” with him, and saw himself as a “complete success”. Will was rewarded with congratulations from the ward nurses (“Well, I’m just doing as I’m told!”). Fiona (69/CC) and Ellie (64/CC) were anxious to follow dietary advice, and after treatment Ellie avoided what she saw as the overuse of specialist nurse support (“You do feel like you’re pestering”).

Expectations of behaviour in breast cancer patients were more clearly associated with normative beliefs about cancer, and focused on responses to chemotherapy and hair loss. Breast cancer participants felt subject to prescriptions about how to behave more often than the prostate or colorectal cancer participants:

...the Macmillan nurse said to me “It’s not a, it’s not a disability and...don’t become a victim”. And that always stuck with us and we used to say, me and [husband]... “I’m not a victim of cancer!” ...She quite narked me off saying that!

Gill (40/BC), Interview 1

Two participants reported communications in which doctors positioned themselves as subject to castigation, implicitly suggesting the existence of a clinical hierarchy within which good behaviour was expected at all levels:

I went to see my GP...she said, "Well I don't think it's anything, they'll probably tell me off, but I'll refer you to the breast clinic". Laura (46/BC), Interview 1

"You got rid of the cancer – for now...I'm gonna pass you back to [the consultant]...I'll need a CT scan, because I daren't pass you back, cos" he said, "if there was anything wrong...I would gerrit in the neck!" Will (75/CC), Interview 1

Where participants were made to feel that their behaviour might deviate from acceptability, this could lead to mistrust and make emotional adaptation to patienthood more labour intensive. Again, this theme appeared more among breast cancer participants. Janet found it difficult to elicit support from specialist nurses – she linked this with an episode in which she suggested that she was not being given enough consideration, given the caring duties she performed for her husband:

The breast nurses who were there were the two I had met previously and they said in their introduction [to a group support session]...if people have concerns could they please come and...talk to us afterwards, not express them direct... they were afraid I'd be a loose cannon...launching out into personal invective, you know! So it made me think...it possibly was deliberate that they kind of like put me on the back burner...but I can't prove this. Janet (70/BC), Interview 2

Eleanor (71/BC), Maura (81/BC) and Mary (70/BC) referred to feelings of being mistrusted or disbelieved during previous health care experiences – Eleanor had been treated for pancreatitis prior to her cancer, and her warning to staff that she reacted to anaesthetic with vomiting was dismissed – “I could see the young man’s eyes rise to heaven as if to say ‘They always say this’. But of course I was bad, so instead of it being a day visit...I was kept in”. Gill (40/BC) and Lesley (43/BC) described how their intuitive concerns about cancer were dismissed:

...when I was waiting for biopsies...it was delayed, and I was getting quite upset... I'd said to one of the nurses...“Well if they don't hurry up,” I said, “this, this lump, I can feel it growing”...she laughed at me and said, “Well, don't be silly, you know it's not cancer, then, don't ya? Cos cancer doesn't grow that fast”...she laughed at me. Lesley (43/BC), Interview 1

Participants wanted to be listened to and trusted as the expert on their own body. Communication that achieved these aims was a key motivator for participants to perform patienthood to the best of their ability.

7.2.2 Pursuing personalised care

Four participants demonstrated an awareness of their role as a consumer of care (2PC/2BC), and the majority were sensitive to the generalisation of patient experience in professional talk. During discussions about treatment, seven participants felt challenged by a professional focus on the worst-case scenario (2BC/4PC/1CC). Tony offered his perspective on the origins of this:

I think that if there is a flaw in the approach from a professional side, is that it's...the sort of fear of litigation, fear of doing something wrong...I mean certainly the worst conversation of all of them...was very much a list of this might occur and this might occur and this might occur...it was much more a "This is what I have to cover"...than the first consultant, who asked a bit about lifestyle... This was much more protective of the industry. Tony (69/PC), Interview 1

At the point of treatment, information provided by professionals could set low expectations about recovery, which participants, in measuring their cancer against that of other people (see section 8.3.3), had to recalibrate to facilitate a positive approach.

The Macmillan nurses give you masses of booklets and things...they seem to really emphasise the downside... they're very much leaning towards the worst case scenario...I suppose it's better to tell you, then you're not going in sort of expecting a nice outcome, then it doesn't happen! Martin (72/PC), Interview 1

...the cancer charities, because they're massively dependent on public donation, they've got to tell the threat story, haven't they?...I don't think the bit that says "All these people get better, and it's fairly routine to get better, and all of these things get sorted", as a chunk, I don't think it's weighted in a way that responds well enough...I think the cancer charities could safely talk about the amount of people they...get back to a normal life, rather than just the impression of end of life care in crisis, and it would be healthy. Tony (69/PC), Interview 2



Figure 13 Eleanor photographed leaflets given to her at the point of treatment.

After Will's worst-case scenario was mapped out, he felt a sense of trepidation:

They was sayin' it, it is a really, sort of big operation...everyone I saw, they kept tellin' me, "It's a big operation". An' I thought, Christ, they're really drumming it into me! Will (75/CC), Interview 1

In the same interview, Will's daughter pinpointed the issue in talking about the information provided prior to treatment: "They can't do it specific for individuals, an' I think that's, that's the problem. They've got to give yer...the prognosis of everything, where you're only a small percentage".

For breast cancer participants, expectations of the worst had also been shaped by media stories focusing on sickness and hair loss during chemotherapy. Breast cancer participants in this study felt that chemotherapy did not live up to its reputation:

I thought it was gonna be worse...after the third one we realised that yeah, I could still do things in between the chemo. Gill (40/BC), Interview 1

The horrors of chemo are exaggerated perhaps...this cold cap system, that does minimise the hair loss...it's rather amusing cos they have stereotypes, pictures of a hairless person! Janet (70/BC), Interview 1

Describing possible outcomes sets expectations – worst-case scenarios could magnify patients' concerns:

You know how just somebody says something that is, like, slips off the tongue, and you know, they haven't really meant to say it quite like that? When I was going through my chemo, the breast care nurse said "All we've got to is make sure you don't get life threatening illnesses during this"...I did get quite freaked out when I thought I was getting a cold one day. Clare (55/BC), Interview 1

Generalised information made it difficult for the participants to determine how recovery might happen. Where care felt personalised, participants found it easier to map out possible outcomes. The personal touch, for Tony, was professionals' ability to conduct conversations which "open out both sides, their lives and your lives":

I think the better of [the professionals] were really skilled at saying, "I've got a job, and you've got a patienthood to get through, but that doesn't stop us being who we are". Tony (69/PC), Interview 1

For James (75/CC), it was being "bothered" to ask how he was, which he equated with dedication – "like any industry, you got your dedicated, and then you got your workers, and you got your shirkers". Janet (70/BC) distinguished between the passive and active provision of personalised care:

...the named nurse system...how unsatisfactory I found that...I feel in any relationship it's got to be a bit of give and take; like if you're forming a relationship of any sort you wouldn't just expect one person to be doing all the contacting, it's got to be a bit of both to build it up...if you just say to somebody, "Well I'm here if you need me", that's sort of a, really like saying "Don't bother!"
Janet (70/BC), Interview 2

For other participants, communication felt personalised by small behaviours – by the deliberate use of the patient's name and the inclusion of family members in consultations, by making eye contact (Gill describes an impersonal consultant: "You are a number with him, doesn't even look at you"), by taking time to listen, and by offering suggestions to alleviate symptoms of treatment rather than dismissing them as only to be expected. The visualisation of cancer tumours in clinical talk also helped to make care feel individualised. Nine participants (4BC/1 PC/4CC) spontaneously described the size, shape and/or positioning of their tumour – Will's tumour was "as

big as your fist”, Liz’s was “as big as a two pence piece but it was really, really deep”, Ellie’s was “flat”. Clare’s was “a bit funny...sort of two lumps not fully divided”.

7.3 Bringing the self into focus

The challenges presented by cancer led participants to reflect on past difficulties in their lives and how they had come through these. They were keenly aware of how illness compromised their sense of self, and worked to maintain their pre-cancer identity by considering existing personal strengths in the light of their new situation. Of the eight participants who were working at the point of diagnosis (5BC/3CC), four (3BC/1CC) felt that their work identity was compromised:

I couldn't go to work, which I was quite upset about...I'm a bit of a workaholic... I missed all that, I felt like, I felt like that was part of me taken away, my identity. And I'm going back next week...I can't wait! Lesley (43/ BC), Interview 1



Figure 14 Lesley’s photograph of her work uniform.

Eleanor (71/BC) and Mark (62/CC) were self-employed, and retained their work identities by minimising disclosure. This was a struggle for Mark as he coped with bowel problems after treatment. Clare (55/BC) maintained regular social contact with work throughout her treatment, undertaking easy work tasks from home, and did not feel the loss of identity experienced by other working participants.

Alternative ways of defining the self were searched for as day to day routines were affected. Retrospective identities, from previous working lives or other areas of experience, were drawn upon. Five retired male participants talked about their time in the army, describing personal characteristics developed in the services:

...you become a bit of a, like I say, an old soldier...if you can do something about it, do it; if it's beyond your control, do not worry about it...if it's gonna happen it's gonna. I learned that a long time ago in the army, that. Pete (75/PC), Interview 1

I went up to see an old friend of mine in the nursing home, he's 95...I said "I got bowel cancer."...He said, "You'll get over it...you'll be alright". And he's an old soldier, same as I was, like...you had that sort of attitude...if anything was wrong with you, you just got on with it...When you're in the forces even though you're amongst men of your own age and...class...you still got to think, there's only you. If anything goes wrong, you got to get on with it. James (75/CC), Interview 1

Seven participants drew on family histories, seeing inherited characteristics as increasing their capabilities:

My father was a man who was able to avert his mind from unpleasant things that were going to happen, eh, which was a very bad characteristic in matters of finance, say...I found it a weakness, but...almost endearing. But, so it is perhaps true that I may have inherited a bit of it...I am quite good at saying...this is a problem coming up about which I can do nothing at the moment, so I won't bother about it until I am in a position where I can do something about it.

Stephen (84/PC), Interview 1

I do come from a line of strong women...I don't mean strong in a sort of Northern with a capital "N", butch sort of way, I just mean that, that, the women in my family, erm, you know, my mother, my aunts, my grandpar[ents]...were sort of feisty, independent characters who coped with difficulties, who told their story and made sure that the people around them – their children and so forth – knew their story, so that could pass on. So in a funny sort of a way I do carry something of their independence and strength and courage and coping in, in me, I know I do.

Eleanor (71/BC), Interview 1

I've always been a strong person; I've had a lot of rubbish thrown at me...my dad passed when I was nineteen...my dad was like the crux of the family...Me mum was an alcoholic, so we had to kinda try and keep her away from the drink and so...plus I had this little baby and I had a husband...you go to the back of everything and you have to focus on other things... when [dad] got taken away you kind of have to think OK, I have to do it meself ...that's how I became the person I am. Layla (44/CC), Interview 1

Realisations about the self focused more on the way things had been in the past, and how this had been reinforced, rather than about the changes brought about by cancer.

Not all identities highlighted by cancer were experienced as positive – some represented an issue to be questioned, resisted or reluctantly accepted by participants. For example, Pete approached his illness with an “old soldier” mentality, but took a photograph of his face which showed an alternative identity:

I thought, well let's take a photograph of this worried man. [Interviewer: OK. So that's somebody you are sometimes?] I try not to be, because you just make yourself despondent. Pete (75/PC), Interview 1

Janet took a pragmatic approach to her cancer, but saw ageing and illness as moving her identity closer to invalidation:

I felt strangely calm about it...I'd got a level of expectation that in your seventies and eighties these things happen, and quite a lot of people I know had had a cancer...the downside is that it's sort of plunged me...into a rather gloomy view of the next twenty years...I don't count after ninety...the next twenty years are going to be increased illness and disability and I don't see anybody can tell me otherwise. Janet (70/BC), Interview 1

In all participants, identities are multiple and changeable, and talking through the negatives can be used as a way of throwing positive personal characteristics into greater relief.

7.4 Managing disclosure

Eleanor (71/BC) points out the sensitivity of cancer as an issue “that people aren’t quite sure how to respond to” (interview 2). Participants took a variety of approaches to disclosing their diagnosis, partly dependent upon the likely response and how they might deal with the consequences. A variety of preconditions existed for disclosure. Reasons participants gave for telling others included a temporary inability to fulfil responsibilities at work or at home; the desire for help with decision-making about treatment and recovery; as a response to genuine interest in how you are; to warn family members that they should go for genetic testing where this is implicated; to prevent speculation about their state of health; and when they felt that there was nothing to be lost by telling – or that there was no good reason not to tell. Reasons given for not disclosing included protecting family or friends from anxiety; not finding an appropriate time to do so; maintaining privacy; other people experiencing greater hardship; and concern about being stigmatised.

Mark (62/CC) was self-employed and felt that disclosure would lose him income – that existing customers might avoid bringing new business, assuming that he was dying. Mark and Pete also felt that telling was a request for support that would be unfulfilled: “What can they do about it, at the end of the day?” (Mark, interview 1). Fiona articulated the differences between people in their beliefs about disclosure – in the radiotherapy clinic, she met a local acquaintance unexpectedly:

...she said, "Well I was thinking, why would Fiona be here?"...what a stupid thing to think... We're only here for the same aren't we? [laughing] But she wouldn't talk about her cancer. She said "What have you got?" I said "Bowel cancer". I said "What's yours?" She went [shrugs shoulders]...she didn't want to talk...So I accept that – that's part of what she wanted wasn't it? Fiona (69/CC), Interview 1

Eleanor described how disclosure “changes the colour of things” – she chose not to tell friends about her breast cancer when she went on holiday with them shortly after diagnosis. Mark described the same decision in telling his family.

... it didn't seem appropriate to sort of spoil this great time we were all having, to, to put a, put a sort of a cloud over that... There was never the space for it to

seem right to say "We're having a wonderful time and by the way [laughs], I want you to worry about this!" [laughs] Eleanor (71/BC), Interview 2

...[wife and daughter] were just going on holiday; it had all been booked when I had me first sessions of chemo...they were away while all this was happening...so that worked out all right...what's the point in tell, getting everybody else upset? ...some people just like sitting discussing it, I don't. Mark (62/CC), Interview 1

The majority of participants found that the opportunity to tell more than immediate friends and family did not always arise. The element of opportunism in disclosure was best displayed in an anecdote described with great humour by James:

It just came up in conversation...when I first found out, and – ah that was it, er, [friend] come in [to the pub] and he said to me, "Ere, I've had another bloody stroke!" And I said, "You what?" He said, "I've had another stroke!" I said, "Bloody hell!" They is mild strokes, but it knocked him back a bit. So anyway, he said, "Are you alright?" I said "No!" He said "Why not?" I said, "I got bowel cancer!" He said, "Bloody hell!" Anyway, talking away and the young barmaid came up and she looked at him and she said, at the two of us, "What have you two been up to about?" I said, "[Friend]'s had another bloody stroke." She said, "You haven't?", he said, "Yeah". So er, he turn round and said, "He's got bowel cancer!" And that's how it got round, see? James (75/CC), Interview 1



Figure 15 *The snug area in the pub where James exchanged his health news with an acquaintance (see quotation above).*

7.5 Engaging your audience

The consequence of disclosure is making the cancer experience visible to an audience – raising the curtains on your illness. For some participants, when distant acquaintances discovered their diagnosis, cancer could begin to feel like an impromptu performance that some people seemed embarrassed to witness. Where disclosure was deliberate, participants faced the consequences – a disruption of interactions, a focus that eclipses all others with every conversation touching on cancer, and a sense of demoting of the importance of the ordinary in the people around you. Retaining an element of control in the face of this required a willingness to engage in a way that worked for each person they spoke to. Participants made choices about their appropriate audience – people who might collude with them in the way that they needed. For many, these choices were initially based on trial and error. Three aspects of engaging an audience are explored below: the use of technology as a curtain-opener – for example, Facebook or Skype, which could expand the visibility of the experience; the continuation or creation of social routines after treatment; and the characteristics of a good audience, and how these might be preconditioned by humour and curiosity.

In managing disclosure, participants made decisions about who should be kept informed about their progress, and how this should happen. Seven participants (five working, one retired, one unemployed; 5BC/2PC) talked spontaneously about their use of technology to engage others during treatment, using Facebook, Skype (video phone), texting and/or e-mail (five participants photographed computers or mobile phones as significant objects). Gill (40/BC) used Facebook as a tool for disclosure, introducing her diagnosis to a large audience. Cancer then became a reason for distant family to get in touch, and observe and comment on her progress. For Laura (46/BC), Facebook was a place where social withdrawal initially played out:

I came off Facebook cos I thought, I was so – “Everybody’s carrying on with their lives, it’s not fair!”...I must have had about a month without it after I got diagnosed, and then I thought, oh, I wonder everybody’s doing? [laughter] Like you do...And that, er, it got the better of me...I got past the resentment of everybody actually [laughs], er, they are entitled to get on with their lives! The world don’t stop because I’ve got something wrong. Laura (46/BC), Interview 1



Figure 16 *Telephones, texts and tablets: photographs presented by Clare (left) and Gill (right), representing the social windows opened up by technology.*

For Clare (55/BC) members of her church became a virtual audience, and she took comfort from text messages about her inclusion in group prayers. Skype was used by Liz (48/BC) and Lesley (43/BC) to offer visible evidence of wellness. The widest circles of disclosure occurred among the breast cancer patients who were of working age, who were more engaged with using technology than other participants.

Participants who were most successful in ensuring company and social continuity were those who had enjoyed established social routines prior to treatment. Thirteen participants talked about their active involvement in social groups outside of the family (5BC/5PC/3CC). Prostate and colorectal cancer patients described social outings becoming compromised by the need to visit a toilet, but the enjoyment of social activities was such that some participants chose to deal with physical symptoms while out and about as best they could. Gill (40/BC) established new social routines with work colleagues during treatment which continued afterwards.

As participants negotiated their way through disclosure, the way that they engaged with others encouraged either support or sympathy, and these concepts were mutually exclusive. Clare articulated how sympathy, rather than providing emotional support, requires emotional labour:

[My colleague's] husband left her last summer, real shock to all of us, and so she's going through that...although they were two very different things, there

was a massive support thing of just, like, being in a place where you don't know you where you...a new place in your, in yourself, in your life, um, and neither of us being over-sympathetic with each other, [laughing] and sometimes being able to say hard things...that was really helpful...quite often it's not people in the same situation as you, but people who can sort of, like, parallel things from their own experience, to bring out an empathy...if I'm struggling myself I don't want to be looking after other people's reactions. And that's the problem with the sympathy, yeah, because then you've got to look after them. Clare (55/BC), Interview 1

Gill (40/BC) echoed this discomfort: "I can't be doing with people's 'Aaaaw!'" (interview 1). This was reflected across all three cancer types:

I'm not bothered about other people knowing in a way, but you don't want to sort of think "Poor old Martin"...I just carried on regardless...there is still a bit of a stigma about cancer..."Oh God, he's on the way out!" Martin (72/PC), Interview 1

...if people start fussing at work I wouldn't wanna be in tears...I don't like concern and "Are you OK?" and, you know, too much of the fuss, I just like the fact [friends] put themselves out to come and see me and to take me out or to do things for me. Ellie (64/CC), Interview 1

Participants looked for an audience who were willing to let them take the lead in how to perform their illness. Displays of curiosity about treatment were also interpreted as supportive:

My cousin she she was, she used to take me [to hospital] then she, she likes to know everything, ohh... She said, "Can I watch when they take the drains out?"...she thought that was fascinating...Everyone's seen me boobs, me nipple – my new nipple, I'm so proud of it! Gill (40/BC), Interview 1

Me granddaughter fusses. Me granddaughter just qualified, a year ago at University, to be a nurse...She wants to know everything – "Are you doing this, granddad?" [laughs] David (80/CC), Interview 1

...the eldest [grandson] who's seven, he wanted to know what was happening at the [hospital]...he got his little picture of all the staff there and the machine and everything. And he still got it on his bedroom wall! Arthur (77/PC), Interview 2

Humour about the physical aspects of cancer was an effective means of engagement, as it reduced the gravitas associated with cancer in the minds of people who had not experienced serious illness, and encouraged the sharing of anecdotes with those who had. Examples of humour occurred across all three cancer types.

When I came out of hospital, one of my friends came round and she brought air freshener, toilet rolls, things to hang up in the toilet so you don't smell [laughs], all sorts of things to try and make light of it... So sense of humour was quite important...try and lighten it up, because it is a serious thing – ooh, CANCER! Ellie (64/CC), Interview 1



Figure 17 *Joke toilet paper, bought as a present for colorectal cancer participant Ellie.*

I joke about it. I make jokes all the time about it. Like one of the lads in pub, he said to me, "What treatment you had?" so I said, well I said er, they put a camera up. And he said, "Well how did they get it up there?" I said "Well", I said "they get two tyre leavers, one each side, open you up and shove the camera in,"...[laughs] He said "He don't, does he?" "Yeah!" [laughs] James (75/CC), Interview 1

I was working Christmas eve til about four and it was dead, there was nobody coming in...I said "I wouldn't mind getting off cos I got to drive to [southern town] with the kids", and [work colleague] said, and we were sat in a group of us and

we laughed about something similar earlier, and she said [pitying tone] “Aaw, everybody, let’s let Laura get off early, because she’s had cancer this year” [laughs]. And my colleagues went [gasp!]...they all dropped their jaw and then [gasp!], as if “You can’t say that!” But because I know her, we were in hysterics...you can do that with close people. Laura (46/BC), Interview 2

For participants who managed to maintain social routines, when treatment was complete, cancer relinquished its central position as social life resumed. It is important to note, however, that some participants who actively wished for a social life found this difficult to pursue after treatment – in particular where comorbidities were present (explored more fully in section 8.3.3).

7.6 Chapter summary

This chapter began an exploration of the findings by drawing on the stories of diagnosis and treatment that arose mainly in the first interviews – participants began by thinking about what had been most significant to them at this time. Becoming a patient disrupted their sense of identity: the generalisation of patient experience by others, and the expectations of behaviour that came hand-in-hand with this, led them to reinforce their individuality and examine what personal characteristics they could draw on to manage the experience. Through a measure of trial and error in making disclosures of their diagnosis, participants learned to shape the audience for their cancer in a way that would provide them with support or, dependent upon their outlook, would simply minimise the difficulties that cancer was introducing into their life. The next chapter moves beyond immediate concerns connected to diagnosis and treatment to the following months, and outlines how social interactions shaped participants’ interpretations of their situation and informed their thoughts about adaptation and recovery.

Chapter 8: Using social resources for meaning-making

I don't like the use of the word... "survivorship" suggests to me that you're one of a small minority, like Holocaust survivor or Titanic survivor... it comes up a lot with [husband], they talk about stroke survivor... it suggests that, you know, ninety per cent of people are dead and you're clinging to the wreckage.

Janet (70/BC), Interview 1

8.1 Introduction

This chapter examines how participants used social interactions to make sense of their situation. All participants, regardless of their social context, had access to resources in the form of other people and institutions. The first section describes participants' stories in relation to the most significant social worlds that arose in interview talk – the worlds of the family, the workplace, and the hospital oncology clinic. *Moving between social worlds* helped participants to make sense of their situation, accepting or rejecting the meanings about cancer offered by others and creating their own frameworks of interpretation. The second section considers how they listened to other people *Laying down the lore* about cancer, evaluated their perceptions, and from these, developed new vocabularies about cancer which were a better fit for their own experience.

8.2 Moving between social worlds

In participants' interview talk, the most salient social worlds were the domestic world, explored in *Belonging to the family*, and the world of work, examined in *Belonging to the workplace?* – work is questioned and re-evaluated as participants adapt to the changes that cancer has imposed on them. A new, temporary world is also introduced into their lives by cancer treatment – the world of cancer patients in the oncology clinic and beyond: *Belonging to the patient collective* examines participants' experiences with others who have been diagnosed with cancer.

A powerful metaphor for the way that we move between our social worlds was provided by Eleanor as she recounted her experiences of walking labyrinths:

It's a metaphor for life really because you're only on one path [laughs]... there's a start and an end. But sometimes when you go through it, as you're walking the path...it interlocks and weaves. Sometimes if there were more, if there was a group of you walking, let's say there were, you know, ten people walking it at the same time, sometimes you're far... you're isolated. You're here, and everybody else seems to be everywhere else. Sometimes you'll find yourself, even though you're at different stages, maybe some people are closer to the centre than others, you're all together. So it's like "Oh, we're all together"...you carry on walking, and then a few minutes later you look up and oh, you're all spread out. And then there maybe another time when the twists and turns are very short. And then another time you go nearly all the way round before you go onto the next twist...it's almost like that's like life as well. Eleanor (71/BC), Interview 2

This captures the fluctuating salience of some social worlds, which come into sharp focus at significant moments in life, and the nature of temporary worlds (such as the oncology clinic), where people cluster together for short periods of time and then disperse again.

The social worlds of family, work and the patient collective provided a secure footing for a range of identities. Within these worlds, participants could measure the severity of their illness against other people's experiences of cancer; they also judged their progress in recovery through their ability to fulfil familiar social and family roles. Where a participant's sense of belonging in any or all of these worlds was less keen, they possessed less resources for contextualising their experience. The interview guide did not deliberately address social worlds – talk about the family, the workplace and the patient collective emerged from the data as the three most salient arenas of social experience. Even those who had retired still referred to their work as something that defined their identity, although this was not deliberately addressed in the interviews. The interviews did deliberately explore participants' notions of "community" – the broader context enveloping their lives. *Defining "community"* examines whether this

had meaning for participants as part of a discussion about support during cancer treatment, and *Feeling isolated* describes situations (both imagined and experienced) which excluded participants from social worlds and the support and alternative perspectives that they offered.

8.2.1 Belonging to the family

Family histories provided participants with a rich set of interwoven stories about illness, loss and recovery. These acted as a barometer of experience, against which participants could measure similarity, difference and likely outcomes. At a fundamental level, participants experienced their family as a self-contained unit, like a single body, parts of which could become diseased or out of kilter: in participants' talk, personal experience of illness (and the vicarious experience of it by others who are close to them) is constantly balanced against the experiences of other family members. Where the family body is out of balance through illness, family members who are healthy work towards its restoration.



Figure 18 *Harriet presented an image of her collection of family photographs.*

Families who took this approach to cancer sensed their physical belonging to one another. Layla described this fundamental support system using a metaphor for the family body – family members provided a “backbone” throughout her treatment:

[Nieces and sister-in-law], without them really [husband] wouldn't have been able to go to work; so they were my backbone really. And [sister-in-law], her mum had cancer at the same time; she passed away unfortunately...she never stopped, she would take her mum to chemotherapy, she would come and pick me up and take me...she never stopped. They were amazing, and without them three I, you know, I wouldn't have been able to get there, basically. Well I would somehow, but yeah, they were my, my backbone. Layla (44/CC), Interview 1

...my chemo doctor said to me, he was examining me and he said "Can I just say, if it wasn't for your husband I don't think you would be where you are now". I went, [tuts] "Thank you," I said, "I'll get him a medal shall I?"...And every time he sees anybody now [husband] says, "I made her recover you know. I cured Gill."... He did everything. He did everything. Gill (40/BC), Interview 2

Ten participants described previous experiences with cancer in the family and this became a source of information and advice. Experiencing cancer also heightened participants' awareness of their genetic links and the possibility of other family members becoming unwell.

It's blokes that can get it [breast cancer] as well, so. I said to my brother, "You oughtta go and see the GP and get yourself checked...cos it can spread all through the family, can't it?...with my mum going through it, everybody knew what to expect. We'd seen my mum go through it. Liz (48/BC), Interview 1

[Husband]'s got loads of different minor disabilities, apart from prostate cancer which he's had for eight years...Our niece has just recently...died of bowel cancer, she had three years of chemo and never was in respite...I remember when my father had the same, he said ... "Do I seem effeminate?...I'm on these, on these female hormones"...I think what is most comforting is people who've been through it, that was my feeling. Janet (70/BC), Interview 1

...my brother-in-law didn't do it [colorectal cancer screening]...when this happened to me [he] did it...he was clear but he was called up...if it han't have been for me having it...he would never have done his. Fiona (69/CC), Interview 1

Participants continued to contribute to the health of the family body during their illness, as well as benefiting from the contributions of other family members. Tony summed this up in talking about his elderly mother:

...we all thought, think of [mum] as an incredibly strong, um, much-loved woman who'd done everything for us really...The five of us are scattered...But we have a, um, a sort of support system wrapped round mum...there's a sort of total family communication around her. Tony (69/PC), Interview 1

Families are a source of activities and obligations that are “ever present” (Tony, interview 1), and where the stresses and fulfilments that accompany family life are relatively balanced, this symbiosis can provide security and continuity.

Family keeps yer going, doesn't it?... The kids knew I'd cope, cos I'd always had to cope with them four and bring 'em up and it was us [laughs], us against the world. Mary (70/BC), Interview 1

The grandkids do, have helped, there's no doubt about it...you get up some mornings and feel absolutely shattered...the grandkids come, and go “Come on granddad!”, and they just get you going...it helped me, you know, rather than, “Oh, you're, we shou...granddad isn't very well, we won't go and see him”. And the wife will tell you the same – she'll say, as soon as the grandkids come, he's better. Arthur (77/PC), Interview 2

Family relationships, even where founded on mutuality, can become unbalanced in the face of illness. Where illnesses and other problems conflate, provision of support becomes more difficult:

The other thing...I thought I'd mention it to you, that for the first time I, after [husband] had his stroke I, I couldn't keep my own diary because everything I do has to relate, you know, I, everything...I've lost all freedom of movement – I can't suddenly say to him, “I'm going out to see somebody or other”, because he'd say, “Oh well, no, but you, you said you'd take me to the hospital”. So we have to have a joint diary. Janet (70/BC), Interview 1

...my mother-in-law now is in a care centre...that's the only downside to old life really, she's ninety-five, she's got very bad dementia and we've been looking after her for years and years and years. Martin (72/PC), Interview 1

...it's an interesting web, isn't it, really...trying to keep all, all bits in some degree of balance? This interesting trapped generation that thought it would be free and isn't; now that there's five generations alive instead of four...we've got our kids coming back in to live here, parents still alive, and we're, we're at the point we should be retiring and relaxing... Tony (69/PC), Interview 1

Where cancer is not the only issue causing the family body to be out of kilter, balancing needs is particularly difficult. A keen example of this was provided by George, whose cancer treatment happened alongside an increasing awareness of substantial memory problems, which he had been told were a sign of dementia. Although one of his daughters had given daily support during his cancer experience, he had noticed that since her own diagnosis of multiple sclerosis, communication had become more sparse:

...she's developed this MS. An' er, she rang me up the other day, but still I can't, I can never get through to her, I can't...ring her and, ring her and it's "Sorry, cannot take this call..." I ring her back a half hour, I says, same call comes back again, you know...I just got to where she rings me. George (82/CC), Interview 1

The motivation to recover winds through stories about family needs, and these stories are more prevalent in the accounts of the male participants than in those of the women. For Will (75/CC), James (75/CC) and Derek (81/CC), all retired, their family role was about more than the provision of practical or financial support – family provided a placeholder for their identity, a place where their presence was highly significant.

...a few days after I'd had the operation, I had a, a dream, an' it was awful. I dreamt that they told me I was gonna die...I wan't worried that I was gonna die, but I thought how do I, how do I tell me wife and daughter that I'm gonna die?...I was always more worried about what'd happen to them than what, than meself, I just...felt that way. Will (75/CC), Interview 1

First time I found out about my cancer I broke down in the hospital I cried my bloody eyes out like anyone would do like. It weren't the fact I had the cancer, it was the fact that I thought I let other people down because me and [wife] had just got married...And my daughter, I was her carer because she is mentally handicapped and I thought well what's going to happen to them two like...I'm lucky, I class myself as one of the lucky ones, that I got over it, and my family can still depend on me to make things go right for them...it's not only the person with the cancer, it's the other people around them. James (75/CC), Interview 1

I used to start thinking, what's gonna happen to [wife] and the rest of 'em if I'm not here? Derek (81/CC), Interview 1

There are counterpoints to the sense of family belonging – and these are not reserved for those who are retired or who live alone. Mark (62/CC) and Pete (75/PC) had deliberately distanced themselves from family. For Mark, the decision not to disclose his cancer was a strategy for avoiding difficult interactions. Mark persisted with this as a way of managing the cancer experience, but for Pete, contemplating life after treatment made him think again – holidaying with his daughter and grandchildren had become a new priority.

I've become a bit of a recluse over the last four years...you're starting to think there's a bit more to life than just plodding along the same little path all the time, you can stick your head above the parapet now and again, take a bit of a chance...you're seventy-five, what've you got to lose? Pete (75/PC), Interview 1

Ten participants had family living relatively nearby; for twelve participants, family members lived in different towns (for three of these participants, grown up children had moved abroad). Where family were scattered, technology could be used to shrink the distance between them.

My family – I have one daughter who's a widow living in [France], and five grandchildren ranging between twenty-two and thirty in age...each of those grandchildren is in a different country...So they're scattered, but they are – it's a good close family, they are supporting at a distance, erm, by e-mail and so forth. Stephen (84/PC), Interview 1

The majority of participants enacted family belonging by deliberately cultivating connections during and after their cancer treatment. This most often happened through accepting practical help, or where family were at a distance, through temporarily increased communication during treatment.

8.2.2 Belonging to the patient collective

For those undergoing treatment for the first time, attendance at hospital clinics opened up a new social world populated by cancer patients – diagnosis conferred insider status. For eleven participants, this patient group operated as a cooperative, offering the exchange of assistance and advice. Treatment units at the local hospital became a hub for discussion:

...the nurses and the doctors were explaining things to me, but you seem to pick up more little details from the other patients – you get what I mean, like? Cos I think there was about six of us in the waiting room. James (75/CC), Interview 1

A really nice lady who was having the same, exactly the same thing as me, she was in her sixties. We've kept in touch actually, we ring each other now and then ...there was a few of us having breast surgery but mine and hers were having the wires inserted because it was so tiny. Laura (46/BC), Interview 1

There was one chap who arrived very worried, he was a mere stripling of sixty!...he'd also previously had an emergency operation for cancer in his kidney... so he'd got a lot more reason for being apprehensive than we had...but during the course of these sort of discussions he appeared to be greatly calm, and I suppose we all were. So in effect that is itself a support group, I suppose.

Stephen (84/PC), Interview 1

Patients gathered in shared waiting areas as a “loose group of people from all walks of life, but with enough in common in this short period of time...there's sort of common purpose, there's a degree of reserve which disappears” (Tony, 69/PC, interview 1). For some participants, this opened up a world they hadn't previously considered:

...until you're diagnosed...it's like so many things, it's something that happens to other people. Pete (75/PC), Interview 1

I didn't realise there was so many people havin' problems...when I went into the chemo, an' I saw all these chairs and stuff, and the beds, I thought, good grief, I, I didn't realise it was such a big thing. Will (75/CC), Interview 1

I think the thing is that you speak to other people when you're in the waiting rooms...the younger women tend to see you and come over cos they want to relate, you know...I was thinking, you'd go to a cancer place, everyone's gonna have cancer, it's gonna be...an unhappy place. It isn't...the nurses are laughing and joking...they know everybody by name, you walk in the corridor, "You all right?", you know. Lesley (43/BC), Interview 1

Eleanor presented a photograph of the curving pathway into the cancer unit she attended, and summed up the implicit camaraderie among patients as they acknowledged one another along the pathway:

...everybody smiled at each other...made eye contact and smiled, and I thought that was a nice gesture. It's like a brotherhood or a sisterhood or something, you know, it's, it's about acknowledging that it's not, it's not the easiest thing in the world, but...we know something about it for each other...part of the going in and out was about that mutual care. Eleanor (71/BC), Interview 1

When treatment was over, a final visit to the oncology clinic allowed participants to compare their situation favourably with those still undergoing treatment. The following section explores how the sense of collective experience was strongest for prostate cancer participants.

8.2.2.1 Joining the prostate club

The effect of the patient collective was most clearly marked among prostate patients: Pete and Tony referred to the social style of the gathering in the radiotherapy unit as a "club". For the prostate patients, social contact usually began with conversation about the difficulties of drinking large quantities of water without visiting the toilet, filling

their bladder to keep it clear of the prostate gland during treatment. Entry into the prostate club was earned through displays of pragmatism, humour and “camaraderie” (Jack) about their shared circumstances. Stephen referred to it as “a kind of fluctuating community of elderly men all with the same sort of complaint” (interview 1).

...it opened at eight o'clock in the morning, and there'd be a group of us sat in the easy chairs outside, so – drinking, dropping water...the prostates you could spot a mile off [laughter] – we'd all got little glasses of water lined up. So it made it quite easy to have those sorts of conversations...so the atmosphere wasn't down, the atmosphere was up. Tony (69/PC), Interview 1

For prostate patients, “club” membership is marked by transitional stages. As treatment progressed, patients graduated from initiates to advice-givers in a matter of weeks, able to pass the group secrets on to the next influx of new members:

From the patient side, um, it's really quite funny...you've got a blindingly obvious first-timers group who are turning up at the machines, who are with their friends or family and looking anxious and very serious...and then there's a group who've been there for a week who usually spot the newcomers and say, "It'll be fine", you know, "in a week you'll be telling others". Tony (69/PC), Interview 1

I got offered a job in the café...a chap had come in and he'd been on chemo... he was going to go on radiotherapy...[café worker] was going to go get him some leaflets..."Hey," I says, "don't worry...you don't feel a thing," I said. "You'll get some little tattoos...it is a narrow bed you get on but don't you worry about it because you don't get off it until they tell you to"...then this [café worker] come back and gave him all these leaflets. So I went in the next day...I said [to café worker] "Hey, I'm sorry I stole your thunder!" He said "Absolutely brilliant. I've seen the machine, I haven't been in it. That chap, he was over the moon because he knew what was going to happen to him." Arthur (77/PC), Interview 1

The prostate cancer participants in this study all attended the same, relatively new radiotherapy unit at a local hospital. The behaviour of the radiotherapy staff and the design of the unit with lounge areas made the formation of a comfortable patient group possible. Tony eloquently summed up how this worked:

...the clinic have got its culture right, it feels led...there is clearly an ethos that people are welcomed, the place is spacious...within two or three days they mostly recognise people by their first name..."Ooh Tony, you're at bay six this morning" ...or whatever. So it's very, very personable...it's all very sort of clear and open, there isn't a protected defensiveness thing about it which is impenetrable for patients...the leadership and style of the professional unit is about upbeat and personal and open and talking, that translates across to the patient group in some way, and so we become that too. Tony (69/PC), Interview 1

Martin described the skill of being personable as “general chatter to make you feel at ease” – an art referred to by Tony as “advanced hairdressing”.

Five of the seven the prostate participants spontaneously talked about the mechanics involved in radiotherapy and their confidence in the “large, expensive machines” (Stephen), which provided both fascination and distraction:

Well it's something about the size and shape of that window there, and it's got arms on the side of it, and a thing on the top of it. When I was a lad I used to go to the cinema and you would see films – whad'ya call 'em? – science fiction films, where a man is dead and somebody puts him on a table and the beam of light goes “hurrrrr”, and he gets up and he goes and takes on the world! And you think well..in my lifetime this has become almost reality! Pete (75/PC), Interview 1

I've learnt all about these machines...I asked...the girls in there, the only thing they couldn't answer was what is the, what bearing is, turns everything? Does it turn on, is it a ball? Is it a roller, this? Arthur (77/PC), Interview 1

This ease with radiotherapy machines was evidenced only in the accounts of prostate cancer participants. It should be noted that the experience of internal radiotherapy for colorectal cancer (three participants) was entirely different. Fiona had not anticipated the depersonalisation she would feel on positioning herself on all fours for treatment – “it was totally, totally embarrassing” (interview 1). Other colorectal cancer participants who had experienced internal radiotherapy (Derek and Mark) did not describe their experiences in the clinic.

8.2.3 Belonging to the workplace?

Eight participants were working at the time of their diagnosis (5BC/3CC – seven women and one man); additionally, Tony (69/PC) continued to undertake consultancy work and was helping his son to establish a business. Where working lives were interrupted by treatment, the break could strip away a level of identity: after sickness absence, participants' capabilities for work could be called into question. For Clare (55/BC), Ellie (64/CC) and Layla (44/CC), maintaining social links with work colleagues was a key source of continuity. Lesley, in contrast, had to cut her ties with work during treatment (this was determined by institutional protocols), and felt that maintaining links would have been more beneficial:

I've tried to go all the way through. But my employers don't encourage going back, stopping, going back...there's probably not a lot of time that I would have been able to go...might have been a couple of weeks on, a couple of weeks off. So might have been a bit disruptive, so. But then it also made you feel out of the loop. Things changed at work. Lesley (43/BC), Interview 1

For Gill, where discomfort at work existed prior to diagnosis, this was escalated by her absence, regardless of her successful maintenance of a social circle from work.

I didn't get on with our area manager...never bothered with me all the time in the six months that I was off...then she stopped all my girls [work colleagues] coming to see me...one of them come, she said "Can I still come? She's told us not to come and see you". And I said "Of course you can come and see me! Why won't she let you?" So she said "Oh, she doesn't want you getting stressed"...there's no love lost there...I am going stir crazy. I do miss it. Gill (40/BC), Interview 1

None of the working participants had returned to their jobs at the point of the first interviews – they were still recovering from treatment. At this timepoint, the sense of loss of identity in the working world was most salient, and support offered by work colleagues was at its most meaningful. As the second interview analysis progressed, it became clear that the return to work would be more appropriately considered alongside interview talk about adaptation and recovery (see section 9.2.3).

The depth of connection between work and feeling valued was also demonstrated by retired participants, who drew on identities from previous working lives to evidence personal characteristics. For example, Derek (81/PC) described his confidence and “natural attitude” in his job as a burner in the shipyards, George (82/CC) talked about his work as a “top rate” engineer. Conversations about past working lives emerged spontaneously from questions unrelated to work. George went on to express his feelings of isolation after retirement – the same sense of loss had been experienced by other participants after retirement, without reference to health issues.

...the work I used to do... manufacturing, you know...an' er, my wife was a shorthand typist...I don't know why it's turned out like this, or why it's so hard... it was so free, me and her, we used to go out places, and go on us holidays, you know. I'd tell 'em at work when I was going to have 'em and all this. Now I don't seem to have any contact like that any more, you know...[colleagues have] most probably died now, you know. George (82/CC), Interview 1

Retired participants who maintained social connections with ex-colleagues (3PC/2CC) had wider networks of social support during treatment than those who did not. For example, socialising with ex-colleagues gave Jack (65/PC) the opportunity to witness other people's cancers and cancer symptoms among men of his own age, contributing to his opportunities for comparing his disease with the experiences of others.

8.2.4 Defining “community”

Participants had little trouble describing the social worlds of the family, the workplace and the patient collective. Views on what constituted their local “community” were more difficult to explore. Definitions of community, and how it influenced support during illness, were diverse and, at times, polarised. Mary (70/BC), Derek (81/CC), Mark (62/CC) and James (75/CC) had each lived on the same urban estate for decades; George (82/CC) and Maura (81/BC) lived in purpose-built retirement accommodation. Lesley (43/BC) lived in a detached house and Gill (40/BC), Clare (55/BC), Laura (46/BC), Liz (48/BC), Janet (70/BC), Arthur (77/PC), Will (75/CC) and Ellie (64/CC) in terraces or semi-detached houses, all in urban areas. Pete (75/PC) and Fiona (69/CC) lived in semi-detached houses and David (80/CC) in a detached house, all in suburban areas. Harriet

(72/BC), Martin (72/PC) and Jack (65/PC) lived in suburban estates with a more rural outlook; Eleanor (71/BC), Tony (69/PC), Stephen (84/PC) and Greg (78/PC) lived in small rural villages and Layla (44/CC) lived in a rural area with few neighbours.

In the first interviews, participants were asked about experiences of support in their local environment or neighbourhood. Just as the social worlds of family, work and patienthood are bound together by shared experience, the most prevalent form of neighbourhood support had emerged from lifecourse communities – social groupings emerging from shared life experiences, such as school networks, parenting young children, army life, and sharing retirement in purpose-built estates. For participants who had remained living in the same city for twenty years or more, these networks were based on shared histories that had persisted over decades.

You build up your network of friends, don't yah?...It's friends and family that really keep you here. Lesley (43/BC), Interview 1

I hadn't seen this friend who was at the tip the other day for – crikey – five, six year. But her mum told her [about the cancer], you see, and she come running up and put her arms round me...we used to be at playgroup together, with her children and some children that I used to childmind. Fiona (69/CC), Interview 2

I've got groups of friends in different spheres; I've got, you know, friends at the squash club, I've got friends going back forty odd, forty plus years still, there's a group of us who initially set up a play, a children's playgroup, a pre-school playgroup, and actually one of those is the one who's just died, but we're all very close. It's almost like a sisterhood. Harriet (72/BC), Interview 1

Every second Wednesday I go out in the evening with my school friends...They're still keen to find out, everybody has been pleased about the PSA [prostate cancer blood test] numbers, so that's been good! Jack (65/PC), Interview 2

While some lifecourse communities survived across the years, others were time-limited – linked to life stages such as pregnancy and active retirement. Enduring lifecourse communities, such as networks of old school friends, could provide consistent support during cancer treatment and recovery. Where social groupings

were time-limited, clustered around specific stages of life, they dropped away – as the patient collective tended to drop away as participants moved beyond treatment.

I used to [know people], well my wife did...used to know most of the people here [in retirement flats]...but now there's a lot of new people come in, which I don't even know who they are. George (82/CC), Interview 1

I don't seem to have any contact like that [with ex-colleagues] any more, you know...most probably died now, you know. Th' used to be two or three of us, we used to go do, you know, go out at night. David (80/CC), Interview 1

When participants were asked what constituted a sense of community, talk about lifecourse communities was the most prevalent response. The strongest community support in local areas was experienced by four participants (1BC/1PC/2CC) who had lived in the same locality for more than two decades, and felt known in the local area:

I've been on this estate really since I was seventeen, so, and I know everybody. I mean I sit on me bench and people, "Hi!" "Hi!" "Hi!" – cars are waving and that, so I'm fine. I think if I had to move off it, this estate, I would be lost. I couldn't live anywhere else but here. [laughs] Mary (70/BC), Interview 1

It's just like a little family round here in this little grove. Everybody knows everybody [Ay, everybody knows] they don't know everybody's business but [Everybody knows too much!] everybody's there to help [laughs]. Derek's wife, interspersed by Derek (81/CC), Interview 2

In estates in deprived areas, participants reported strong social cohesion over decades. In contrast, Maura (81/BC), Pete (75/PC) and Eleanor (71/BC), who had moved to their current location from other cities, described a sense of exclusion from – and in Maura and Pete's case, a sense of resistance to – involvement with their local community. Their different places of origin made them feel like outsiders:

I don't talk to many people, because all the others are from [this city], you see, and I'm not from [this city]. Maura (81/BC), Interview 1

Is this on record? I've been here, what, nine years now, and I'm, I, I'm starting to pick up bits of the language like, you know, "How much? You what?"...it seems as though around [here] is [pause] devoid of a sense of humour. I'm used to, where I come from, a bit of banter in the shops...Like you make a little joke in the shops...here they go, "Pardon? Sorry but I'm not talking to you". And my wife used to say to me "Why do you bother?" And I'd say "Because it amuses me... Passes my day". So in answer to your question, how do I do over here? It's OK.
Pete (75/PC), Interview 1

James (75/CC), who had lived in the same city for forty-eight years, described the willingness of neighbours to “keep an eye” in an estate where he had experienced local youths urinating in his garden, but a resistance to becoming further “involved” with one another. The value of neighbourliness was contested by participants – Laura (46/BC) and Janet (70/BC) felt little sense of local support.

Nobody's really offering a lot...let me know if you need any shopping, but nothing very proactive; nobody bringing meals round or anything. I don't know, neighbourliness, I don't know...I mean the very fact of people living next door to each other, just the physical, that is a link, but...not a huge feeling of community, no, not really, no. No, nobody's...being very proactive, but I don't expect that, wouldn't really expect it. Janet (70/BC), Interview 1

Other participants – notably, Derek (81/CC), Fiona (69/CC) and Stephen (84/PC) – described “popping in” on neighbours to socialise or to offer help, but this was a pre-existing habit in their neighbourhoods rather than centred around help-giving during cancer treatment. Harriet and Layla recognised “popping in” as a neighbourly activity, but did not practice it. The pressures of working lives were cited as removing the conditions necessary for neighbourliness, and expectations of help were low:

it's not really a community and, to be fair, I don't get involved, I'm quite, I just, I kinda just like my family, close knit things really; I, I'm not one to go out into someone's house and have a cup of tea...I always worked full-time as well, I would just come out my door into the car, come to work, and then that was it from day to day for me. Layla (44/CC), Interview 1

I've never been the sort of person to be in and out of other people's houses for tea, coffee, etc, can't be bothered with that, cos I think one, it's trivia, and two, they're often just gossiping about [laughs] people and I'm, that's not my scene.

Harriet (72/BC), Interview 1

...it's not like that, not community-wise. People are in and out to work and things like that, yeah...I remember the other year when we had really bad snow and we were snowed in, and I was trying to clear my drive, and erm, the road was so thick with snow, and somebody who'd I'd never met before came across from there [housing opposite] and helped me, and you think, God! I was real surprised, I don't even know yuh! Laura (46/BC), Interview 1



Figure 19 *Derek's initial means of getting around his local neighbourhood, which soon became superseded by a mobility scooter.*

Mary (70/BC), Will (75/CC) and James (75/CC) described how neighbourliness and cohesion in the local area became diluted as people left their local area or passed away, and new people moved in. The movement of people brought a sense of displacement, which was also experienced by retired participants when major family events precipitated their relocation in an effort to preserve the family network.

Eleanor found herself displaced at the point of having children, and describes not only a community in transition in the area she moved to, but also how attempts to join an established community felt like an “alien...sort of unknown scenario”. Martin also described the contrasting experiences of living in an established community and joining a new one:

I think we're all of, of a, a generation where, where, where we used to live, and I've still got that house now actually, but it, all the family were dotted around in streets nearby, and that's the way it was in those days, and, you know, the thoughts of moving out of town were, you know, pretty out of the question really.

Martin (72/PC), Interview 1

I did get to know people who had children around the same, about the same time as me...all of them were local, and so this conversation about, you know, “How about a babysitting circle so that we can, you know, get out and about?” was like, “Well no, I don't go out”, was one, and another one was “Why do I need to? Cos I've got my mother next door” or “I've got my sister up the road”. They looked at me as if I was a bit odd. And at that time...there weren't so many strangers in the village, it was much more of a sort of generational family sort of situation. Eleanor (71/BC), Interview 1

Eleanor's social support during her cancer treatment came from family and close friends who lived in other areas, rather than from people in the local community.

8.2.5 Feeling isolated

Social resources were not taken for granted – seven participants acknowledged the benefits they enjoyed by imagining how it must be for people without family – facing cancer alone was assumed to be a route to isolation and unhappiness:

...there are sort of half a dozen people [you meet at the clinic] that stick in your mind as, as characters that you just personally wish well and wonder what their life will be like next. I'm conscious that there were people amongst that group

who never had anybody with them...who looked as if they were going back to somewhere fairly empty too, and you wonder how that works.

Tony (69/PC), Interview 1

I always feel so sorry for people who are maybe in my position and haven't got any family or friends, it must be pretty grim...this morning I went out about quarter past seven and there's an old lady tottering past and she sort of stops people to talk to them...poor lady, you know, she's obviously on her own and lonely...she seems to be out at the crack of dawn every day...just to get out and see people I suppose... if you do have family it does make a huge difference.

Martin (72/PC), Interview 1

Three male participants – Stephen (84/PC), Pete (75/PC) and George (82/CC) – lived alone after the loss of their wives. Stephen lived in village where residents actively socialised with one another, George in sheltered accommodation with other retired people, and Pete lived in his own house on a suburban estate. Pete expressed a sense of isolation – first brought about by moving a long distance away from his home town a few years earlier to be nearer to his daughter, and again by his diagnosis of cancer (he did not talk about the loss of his wife):

...if people say "How are you doing?", if you said, "I really feel rotten, I have had a terrible time", they say, "Oh, oh...is that the time?" [laughter] What they're saying is, "How are you but don't tell me." Pete (75/PC), Interview 1

George felt cut off from his family, who lived in another town, and talked a great deal about the loss of his wife, who had made social connections easily. Becoming a widower and the onset of dementia made socialising difficult, and he expressed confusion over his diagnosis, with no-one to help him make sense of it – the only conversations about cancer he described were those with health care professionals:

I was devastated when they told me that they thought I had cancer...then this doctor...called me in and told me about it, and I didn't know whether to look at him, or talk to him...I know I were so devastated by this, being told that I had cancer...So I said, "Well I've no aches or pains anywhere down there, or anywhere at all", so he says, "Down where?...It in't down there" he says... I were so sick by

this...this cancer business... One day this nurse says... "You got to go in and have a blood test", you know. But I think she were a Macmillan's nurse...she came back, she says, she says "Your heart's fine, you've nothing wrong with your heart! An' your blood's perfect" she said, "just waiting for one result now"...So about half an hour she came back, she says "That was perfect as well!" Says, "There's nothing wrong! You've no need to come any more!" George (82/CC), Interview 1

Of the female participants, four lived alone – Maura (81/BC) and Mary (70/BC), both retired, had separated from their husbands earlier in life; Laura (46/BC) and Ellie (64/CC) were in the same position but still working. Maura and Mary enjoyed close contact with family, and Laura and Ellie a high level of support from friends. The female participant who expressed the most frustration at her social isolation was Janet, who lived with her husband and had been his carer since health problems had left him with severely reduced mobility and suffering with pain during the night. Janet found herself isolated during and after her cancer treatment, and felt that her status as a married woman had led to assumptions about her need for support that ignored the context of her life:

...we had a lot of trouble contacting carers and social services – cos I didn't know how ill I was going to be, and they didn't actually explain to me there is a pathway through the Macmillan nurses... for people who need social care... because I seemed middle class or articulate...they kind of stereotyped me – "She can cope! Been married for 50 years!" Janet (70/BC), Interview 1

Feelings of isolation were as dependent upon contextual factors as on whether or not participants lived alone. For Janet, this emerged from her caring responsibilities and how this work stole time from both her and her husband. Communicating with others is the glue that holds participants' social support together, but requires time and deliberate effort. Pete (75/PC) described how communication dissolved when he moved towns, adding to his feelings of displacement:

The trouble with old friends is, distance and time stretches the lines of communication, and if you don't meet up now and again and strengthen them

then eventually they twang [snaps fingers] and bust, and that's it, you know.

Pete (75/PC), Interview 1

For George (82/CC), cognitive difficulties affected his ability to communicate, despite the availability of company in his accommodation block. With a lack of social interaction, he had little opportunity to listen to and consider different perspectives on his situation. How other participants made use of other people's perspectives is explored in the next section, *Laying down the lore*.

8.3 Laying down the lore

As participants made sense of their diagnosis and treatment, they encountered a multitude of cancer stories given voice to by lay people who had not experienced cancer first hand. Participants framed their own thoughts about cancer in part through critical appraisal of the cancer talk of others, claiming a position of authenticity as a cancer patient. *Laying down the lore* considers how cancer is framed by people who do not have direct personal experience of the illness, and how the study participants made meanings from other people's talk by deciding which perspectives to accept and which to reject. *Filtering cancer talk* examines the most prevalent responses to disclosure among other people, and the decisions that were made by participants about which responses to accommodate within their own frameworks of meaning. The way that participants related to the label "cancer survivor" are explored in *Defining "survivorship"*. Interactions with others who had experienced or closely witnessed cancer in the past are then considered in *Measuring your disease*.

8.3.1 Filtering cancer talk

Making sense of novel experiences, from a symbolic interactionist perspective, occurs through engaging with other people and the way that we reflect on this. Social norms – implicit rules governing what is acceptable behaviour in a specific group or society – are evident in the responses of other people to participants' situations. As participants listened to or read comments about cancer from other people (in conversations, in greetings cards, on the internet, and in consultations), they negotiated with others' ideas about how cancer is experienced and how people with cancer were expected to

behave. This section explores the tension between normative perspectives and participants' subjective experience. Through the data, what became clear is that defining cancer and defining your own individual cancer are different processes.

The meaning-making process took time – the concepts involved in conversations about cancer left participants questioning, interpreting and rationalising in order to construct their own frameworks. This theme emerged in the first interviews, but was left incomplete: at the point of the second interviews, participants had reflected further on the existential issues that arose for them as they talked with other people. This section examines participants' responses to the three most prevalent lay beliefs they met with in conversations about cancer: that cancer is a death sentence (*Defying death*), that the cancer patient must accept a level of personal responsibility for developing the disease (*Taking the blame*), and that cancer is a visible disease which makes genuine sufferers look and feel ill (*Feeling fine*).

8.3.1.1 *Defying death: perspectives and possibilities*

In the first interviews, participants described the impact of other people's feelings about cancer on their own thoughts and feelings, and on their reasons for disclosing:

I haven't felt worried or frightened by it or by, or indisposed by it particularly – it's the impact on the other person. You know, they see that word [cancer] and it's like "Ohhhhh", isn't it? It's still, it still generates that sort of, that scare, that anxiety, that, that eh, negative. It's a scare word. Eleanor (71/BC), Interview 1

So you can't go round everybody and start saying, "Oh look, there's a good chance I'm, I'm gonna die"...What good's that gonna do? So – they won't bother ringing you up, they won't – so apart from everything else you lose yer friends...That's the way I looked at it anyway. Mark (62/CC), Interview 1

The changing landscape of treatment and outcomes – how much these have improved in recent times – was often referred to by participants as a way of distancing themselves from the perception of cancer as life-threatening.

You see all the adverts as well and how much research is coming along and how good it is and I think, no, I'm not going anywhere, I'm not going anywhere, and I'm certainly not going to sit here and worry about it. Laura (46/BC), Interview 1

There is still a bit of a stigma about cancer, isn't there? You think, oh God, you know, he's on the way out [laughs]...I don't see it that way at all, I think with modern treatments and things there's a very, very good chance of success, and so you're best to carry on really and keep your interests going.

Martin (72/PC), Interview 1

Well, that word "cancer"...it's a horrible word, and [pause] I think initially you imagine the worst, but then you realise they can do something about it... somewhere in the past you thought it was a death sentence, but it isn't.

Harriet (72/BC), Interview 2

Cancer is a frightening word but it's a lot more curable nowadays than it was when – I mean both me mam and dad died of cancer, so. I think you know, nowadays we're a lot luckier. Mary (70/BC), Interview 2

Without exposure to the clinical viewpoint, which challenged negative associations about cancer outcomes, the people around participants focused on previous experiences of loss connected with cancer among families and friends. The association with loss coloured their reactions to diagnosis:

It's the word "cancer". It's the word "cancer". And it's the same with everybody, when they found out "cancer", you immediately think, I've, you know, dying... My husband lost his mum to breast cancer...he couldn't see anything positive, so it was hard for me to be positive. Lesley (43/BC), Interview 1

Let's be fair, I don't think everybody's the same, but it's a naughty word, "cancer", innit? You know what I mean? – once that I found out that I had cancer [pause] I was a bit devastated...that's the death sign, innit? Everybody that I've known who's had cancer, they're dead within six month.

Derek (81/CC), Interview 1

My husband was welling up...he'd lost his mum about ten years ago, then we lost his granddad at Christmas to cancer as well... And obviously he's thinking, oh God, the same is gonna happen to me and that. [Son] was, he was a bit distraught... "I don't want you to die mum". I said "I'm not gonna to die, I've got breast cancer. Nanny's still here." [Liz's mother also had breast cancer] But his friend's mum died at Christmas. She had breast cancer, and they said they'd cured it, but then it returned. Liz (48/BC), Interview 1

My father-in-law said to me when I told him, he said "Don't get a thick book". [Interviewer: Meaning?] That I wouldn't be able to read the end of it!... "Why have you said that to me?"...he said "Well, you know!", and I went "No, I don't!"...he did think I was going to die...like how...[husband]'s mother went...Even now he says to me, "You're not well". I said "I am well, I'm fine"... and you know. He keeps going "Oh well, you know, you, you've been very close". Gill (40/BC), Interview 1

Martin offered the contrasting viewpoint – he had watched his wife recover from breast cancer twenty-four years earlier and a recurrence four years later:

It's not a death sentence when you're [laughs], when you're told you've got it... I don't feel any fear of anything...we're used to cancer, because when my wife got it, it was like, oh gosh, you know, death sentence, you know – we just, we'd never really come across anybody who had cancer...She's just been discharged actually after all these years...so now I think it's lost its stigma to a large extent. Martin (72/PC), Interview 1

Mary displayed the same understanding of the possibilities of recovery, having proved this to herself by recovering from cancer in her leg two years earlier. For her, it is an underlying attitude that is not shared by everyone:

I have friends that, they are better [from cancer], but they've never really got over it. You know, they still think, "Oh, I've had cancer and I'm going to die", and it's ten years later. Mary (70/BC), Interview 2

8.3.1.2 Taking the blame: culpability and guilt

Seven participants raised the subject of culpability – whether they were responsible for causing their cancer – when talking about their conversations with other people. All of these participants were women (5BC/2CC). For some, considering whether they were culpable for their cancer began by questioning why it had happened to them – others (notably women over the age of seventy) felt that cancer was associated with ageing, and partly to be expected. Colorectal cancer participants Layla (44/CC) and Ellie (64/CC) were the only interviewees who directly questioned why they had cancer:

I'm not ready to die yet and, you know, I've got to look after my kids...but then mostly I just got on with it...I had to fight it like most people do with any illness really. You ask "Why?", you know. "Why me?" And... [upset] sorry.

Layla (44/CC), Interview 1

I think when you're younger and it comes at you, yeah, you do need support, cos you do think "What have I done? Why me?" Ellie (64/CC), Interview 2

Breast cancer participants Eleanor and Janet took a different perspective:

I haven't, haven't looked back and said, "Oh God, why me? Is it because I didn't do this or because I did do that or because I should have done so and so?" I'm not I'm not one of those persons. So it's, it's just, why not me?...Two out of every three women over seventy get breast cancer, I think – or is it one out of three?...I'm in the norm...in a sort of fairly common situation, I think, for people of my age. Eleanor (71/BC), Interview 1

Clare Rayner, I don't know whether you've heard of her? Yes, she, she had breast cancer when she was about seventy-two or three...She, like me, sort of felt that it was what was due, you know..."Why not me?" Janet (70/BC), Interview 1

The response of others to their cancer treatment could lead to participants indirectly questioning the reasons for their cancer, struggling with the concept that the disease is a result of poor health behaviours or weakness:

Disbelief, absolute disbelief in lots of cases – "How can, how can you [have cancer]? You're so fit and healthy and you do all the right things." And, you know,

cos we have a good diet and we have exercise. OK, I like a drink, and possibly on occasions I might have one or two too many, but I mean we're not big drinkers, we don't smoke, we're fit and healthy, have a good diet, and in lots of cases it was disbelief, you know, "How? Why?" Harriet (72/BC), Interview 1

...somebody said, oh, I couldn't have, "Can't understand how it's happened to you, cos you're so strong", an' I thought, "But it...", you know, in my head it like, well it happens to anybody, doesn't it? You know. I don't think that way.

Clare (55/BC), Interview 1

Breast cancer participants Lesley (43), Clare (55), Harriet (72), Eleanor (71) and Janet (70) talked about culpability and chance in broader terms. On discussing cancer with people, they began to merge their own experience with vicarious experiences taken from books, newspapers and even insurance documents, and build a picture of "causes" of cancer perceived by others to be within personal control. Janet felt that public health promotion took some responsibility for feeding feelings of guilt:

...health education has this huge drawback; I mean it's wonderful really, but it has a huge drawback that when people get like a stroke, and some people have said to [my husband] in quite, you know, he had put on a bit of weight – not, he wasn't obese or anything – but said "Maybe you had the stroke because you'd put on weight". Make you feel terrible, you know. And health education's all very well but it tends to make people feel guilty, you know: "Did they do an hour of exercise...every day?", and this sort of blah-de-blah. Janet (70/BC), Interview 1

Lesley described receiving a gift with an implicit message of culpability attached:

My sister bought me a book on breast cancer. [laughs] I did read it, but it was very American... they blame breast cancer on, um, sugary diets. So you're reading that and blaming yourself, totally [laughs]...I mean my sister-in-law, think she reads a lot in the papers on breast cancer, she brought some chocolates down one day, then she went, "Aah – shouldn't have given you them, should I?" An' I went... "Why?"...She went, "Oh, no, [quietly] cos sugar causes cancer, dun't it?" [pause] So she'd read that in the papers. Lesley (43/BC), Interview 1

The most prevalent associations between lifestyle factors and cancer raised in the consciousness of participants were poor diet or weight-gain (Ellie, Harriet, Janet and Liz), not breast-feeding for long enough (Janet), and work stress (Ellie). In being forced to think about these issues by others, participants looked to find ways in which they had minimised their chances. While areas of perceived culpability were acknowledged, these were talked about in terms of guilt and fatalism – talk about the potential reasons for developing cancer did little to help motivate changes in health behaviours:

But I am overweight and I've got high blood pressure, so exercise has been something that, well it's, I would imagine being overweight and not doing enough exercise are the two factors against me for getting the cancer. But, as I said, the dietary, all the food and: beans, lentils...I had plenty of fibre, it certainly weren't a lack of fibre that gave me it! [laughs] Ellie (64/CC), Interview 2

I look at my diet more – it keeps coming up, cos every time people talk about breast cancer, they say reduce your risks by keeping your weight down, eating healthily, and that tends to be people's perceptions of why you get breast cancer. People say to me, "Oh, how come you got it then?"...Or they put it down to, cos I was on HRT at the time...Well just sometimes these things happen just randomly, you know, they don't know why. Lesley (43/BC), Interview 2

I've never lost weight in adult life, I've tried occasionally...my NPI [National Patient Index, used by insurers to gather information on health from various data sources], when you get these copies of letters...they put all your details into the computer, including the fact you're over eleven stone and that sort of thing you know, and: "Moderate". Well, I'd like "Good"! I don't really like "Moderate"...you feel it's your fault if you tip over into obese, and doesn't take much to tip over. Janet (70/BC), Interview 2

Janet perceived further opportunities for feeling guilty in the onus to check breasts for lumps, expressing an envy of other types of cancer:

It was a bit about negative emotions on the diagnosis, which was a measure of guilt – should I have checked it? Should I have discovered it earlier?...twenty, thirty years ago when I used to get these leaflets about how to examine your

breasts...I did it once or twice terribly scared, and then I was able to stop because the prospect of breast cancer just wasn't a reality to me. But now it is a reality, so I'll have to do these checks, because otherwise I'd never forgive myself... I wouldn't be able to blame anybody but myself... [breast cancer] might be unusual among the most popular cancers in having an element of personal, an own-ness, you know, personal responsibility...I rather envy these other cancers: nowt you can do about it! [laughs] Janet (70/BC), Interview 2

The data did not provide enough evidence to suggest that gender influenced feelings of guilt about previous health behaviours, but did suggest potential differences between cancer types in relation to this issue. Prostate cancer participants did not raise any issues of culpability: talk about its uniqueness among cancers – its high prevalence and how slowly and invisibly it grows – suggested that these issues might mitigate against feelings of personal responsibility.

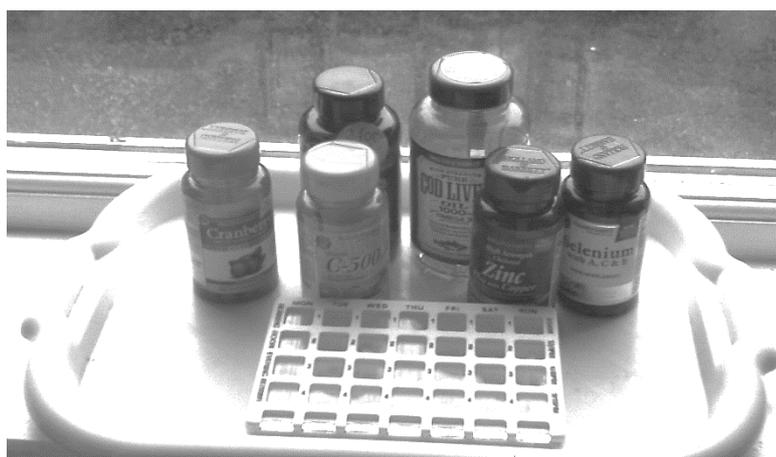


Figure 20 *Martin's food supplements, to ward off poor health.*

8.3.1.3 Feeling fine: disbelief and fraudulence

Half of the participants commented that they did not construe cancer as something that made them feel ill. Thirteen participants (5BC/5CC/3PC) talked about the irony of feeling ill because of the treatment rather than the disease (which did make the majority of the breast and colorectal cancer participants feel unwell). This often arose in the context of communication with others who were bemused by their appearance of physical wellness. It was a challenge to respond to these comments – for some

participants it signified a level of disbelief that brought discomfort or irritation.

...at no time did I feel ill, at no time did I feel particularly scared...people would say "How are you feeling?" and I would be saying "I'm absolutely fine", because nothing had happened, you know! Eleanor (71/BC), Interview 1

Well everyone keeps saying to me, when I tell them...well you look so bloody healthy...I still got it no matter whether I look healthy or not...I think what people thinks is if you say you got the C, the big C, they think you're going to go from eighteen stone, chooom, to seven, you know what I mean? Just go whooom, and that's it. And you're walking about and they all go, "He's got the big C, him". But when you're walking about normal and you're laughing and joking about it, think oh, they don't really believe you, like. James (75/CC), Interview 1

Everybody's said that, that I've looked well throughout, and people that don't know that I've had it wouldn't guess... "How are you?" "Fine!" [laughs] Jack (65/PC), Interview 2

For colorectal cancer participants, the disease seemed invisible where it had not manifested in symptoms – Ellie (64) and Fiona (69) had been diagnosed through routine bowel screening, and found this a challenge. Ellie, Fiona, Will (75) and George (82) suggested that at moments, they had difficulty believing in their own cancer:

[Tears beginning] I'nt it weird? Why do I cry about it? It's thinking back to how I felt, I think. I think so, cos at the time I thought, it was so fast, so sudden. And I, I was thinking, well I had no symptoms. If I had seen blood in my poo, I'd been frightened and wanted rid of it – but I hadn't anything. So yeah, you believe what they say, that you need something sorting out, but [pause] there was a time when I thought...why are they taking it [part of bowel] away? It was just [pause, teary] difficult to get your head around so quickly I think...I remember driving along and thinking – I've got cancer. Why? How can I have? You didn't feel ill...I've tried to put it away, but yeah it has, I suppose, it did really affect me, obviously, up here [head], more than down here [tummy] really. Ellie (64/CC), Interview 2

I used to think to myself, d'you know, I'm wastin' my time. An' I used to tell 'em, you know, I said, "Nothing wrong with me!" "There is, cos I've seen..." you know, the consultant did. "Oh, you've got to do it [treatment]!"...So I said, "You're the boss, you do what you want, like!" George (82/CC), Interview 1

...they all kept telling me that, "You look so well!"...I find it hard to believe I was in such a bad way, and I've recovered from it so quick and clear. It, it just surprises me. An' I thought, are they just saying that just to make me happier, or what? Will (75/CC), Interview 1

Eleanor expressed the idea that she couldn't claim to have been genuinely ill:

There are times when – this sounds very strong – there are times when I have felt like a fraud, because it has been so mild and so un, un, un-painful...you know, I haven't been unwell, I haven't been in pain or anything...and that's another reason why I suppose I don't talk about it that much really – it's because it seemed so easy. Eleanor (71/BC), Interview 1

Janet referred to the same feeling of fraudulence – not living up to the expectations of others who assume that you should look or feel unwell. This caused tension in social interactions: the verbalisation of surprise that a participant looked well could be difficult rather than reassuring, as it failed to acknowledge their situation.

8.3.2 Defining “survivorship”

The concept of survivorship was not deliberately addressed in the topic guide for the first interviews, but Lesley (43/BC) questioned the use of the term in the study documentation: “When I was reading this [study information] and it said about “survivorship”...I don't feel like a survivor!” (interview 1). Eight participants talked about the “survivor” label in their first interviews. Only James (75/CC) and Greg (78/PC) felt that it was an appropriate term for their own situation: six participants (3BC/2CC/1PC) felt that it did not apply to them. For some, the word had negative connotations:

For me it's not an appealing word, but I understand...that for some people it may be, because maybe they have been closer to death than I feel I have been...they really are having to fight to keep going, to feel better, to, to, to cope with sickness, to cope with whatever the side effects can be, maybe for them it is a very appropriate word but I've, I, I feel that I haven't needed to do any of that.

Eleanor (71/BC), Interview 1

I don't like the use of the word...it suggests that, you know, ninety percent of people are dead and you're clinging to the wreckage. Janet (70/BC), Interview 1

In the first interviews, Lesley (43/BC), Laura (46/BC), Liz (48/BC) and Layla (44/CC) associated the term with being two or five years beyond treatment when they felt there would be less likelihood of recurrence. At the point of second interviews, it was becoming an acceptable term for Lesley and Clare (55/BC):

It's a word that, I suppose, simplifies what we are, cos we have got, we've survived. You see to, to me, every week is, is like a, kind of a blessing, because cancer comes back and that's, if, if anything it, I'm frightened of is, that's what my fear is, and you know [oncologist] said "If it comes back, it'll come back within the next two years", and that's why I have scans every three months. So until I've got past this, these next two years, I don't class meself as a survivor.

Layla (44/CC), Interview 1

You do see things around about survivorship...My friend'll say something like "Ooh yeah, cos you're a survivor", an' I go "Yes, I am!" [laugh]...It's just length of time, an' as time goes on, you just feel like you've got past it.

Lesley (43/BC), Interview 2

Ideas about survivorship were deliberately explored with the seventeen participants who took part in second interviews with the question "What is a 'survivor'?" Tony (69/PC) saw survivors as people trapped in a "funnel of difficulty", unable to crawl out. Ellie (64/CC) and Will (75/CC) associated it with having a greater likelihood of eventually dying from cancer, an outcome which they did not seriously entertain during their own experience of the illness. Eleanor (71/BC), Ellie (64/CC), Tony (69/PC),

Mary (70/BC), Stephen (84/PC) and Jack (65/PC) talked about their own cancer treatment and recovery as an experience that did not warrant the title of “survivor”:

I feel as if I've been let off lightly...I've skimmed in, I've jumped into the cancer mire and crawled out of it kinda thing... I don't feel like I'm a survivor, I don't feel as if I've been that near to death. Ellie (64/CC), Interview 2

I haven't joined the survivors' group. I am a member of it, I suppose, technically. A survivors' group...would be set up for people who come out of it very depressed...It seems a completely overcooked word for me...there doesn't feel to have been a crisis to have had to survive for me. Tony (69/PC), Interview 2

I don't class myself as a survivor, no...I think they expect you to live, more to live than to die. So I think if you go in with the thingummy that “I might not survive” you'll come out thinking “Oh, I'm a survivor!” Whereas you should go in thinking well I'll, it's just an operation and I'll be out and back to normal, you know.

Mary (70/BC), Interview 2

Oh I don't feel like a survivor. If, if I'd had a different cancer, supposing I had had bowel cancer...had an operation, gone through the statutory five years...then I would be a survivor. But I've had... I had a, minor effects...a painless operation, relatively trivial side effects... it's all been a nuisance, but...I'm not a survivor.

Nobody shot me. Stephen (84/PC), Interview 2

Janet (70/BC) saw herself as undeserving, positioning herself “with the people at the bottom of the heap, feeling they haven't earned their stripes!”. In trying to define what kind of cancer experience might make someone deserving of the “survivor” label, Laura (46/BC), Tony (69/PC), Will (75/CC), Stephen (84/PC) and Janet (70/BC) offered the experiences of other people for whom cancer had been (or continued to be) more difficult. Stephen summarised this using the example of a head and neck cancer patient he knew through his local community:

Well, what is surviving?...there's erm a fellow, he doesn't live in the village, but he frequently visits, and I don't know what the nature of his cancer was, but the necessary treatment was to cut out not only the, the cancer but a considerable

part of his jaw...the other day he had to go...for further reconstruction and his surgeon...said "I don't think this has worked"...he said, it's disappointing if it hasn't worked, but you know, at least he's no worse off. Now he is a survivor, he's lived for about three years since this business. Now if you want survivor feelings, he's got a right to survivor feelings. Stephen (84/PC), Interview 2

8.3.3 Measuring your disease

Comparison and contrast can be useful tools in making sense of treatment where a long term prognosis is likely to be good. Participants in this study measured the level of difficulty of their own cancer against that of other people's cancer as a way of minimising the negative aspects of their own situation; participants with significant comorbidities measured the level of difficulty of their cancer against the difficulties they experienced with other health problems unrelated to cancer.

When you think you aren't coping, there is somebody always worse off. It's awful to say but there is somebody always a little worse than what you are.

Gill (40/BC), Interview 2

As participants measured their own experiences against those of others with cancer, they reframed their position in the hierarchy of difficulties associated with the disease. Comparisons were based on the severity of symptoms, or on age at diagnosis:

...that woman though when I was in the radiotherapy...I was in that room and that woman told me, "Ooh it burned me" [laughs]...Poor woman, I thought, cos she was getting' on...like that bloke, he was having radiotherapy and he was in a bad way, and they kept him in, and me daughter said [to him], "You look better"...she saw him again later on...and she said he didn't look too good.

[nervous laugh] I did feel sorry for people. Will (75/CC), Interview 1

... some had been through worse things than me...I remember speaking to one, the wife of one patient, and she'd said that every time they'd been for another consultation it had got worse, and I said well mine had been the opposite really, mine's got better each time; so that was a bit worrying for her.

Jack (65/PC), Interview 1

I had my results on April the 17th, and said it was clear, it was, it had worked, which was obviously totally amazing. But then I went outside into the waiting room and I saw all these other people who were still poorly and it was like maybe I shouldn't feel as happy as I do because other people were still suffering.

Layla (44/CC), Interview 1

I'm seventy, and when you go there and you see twenty/thirty/forty-year-old women, it shouldn't be happening...I felt as if it should be me there and not them...my metabolism and me hormones aren't working... I'd have willingly took the chemo from – I mean one of me friends, me daughter-in-law's friends, she's got it, me son's friend, she's got it, and they've both lost their hair and been through chemo, they're both in their thirties... if I'd have gone and they was all right it would have been better... I've had a good life, I'd had four beautiful sons, I've got nineteen bloody grandchildren! [laughs] Mary (70, BC), Interview 1

The effects of cancer were also measured against other health problems. Eleven of the retired participants suffered from other health issues, including blood pressure problems (2), long term musculoskeletal pain (2), diabetes (2), stroke (1), heart problems (2), early dementia (1) and neurological difficulties (1). Two other retired participants had suffered from acute episodes of poor health (Eleanor with pancreatitis, David with an aneurysm). Cancer was, without exception, placed lower down the ladder of difficulty:

When I was ill seven years ago and got this acute pancreatitis, I spoke about that a damn sight more than I speak about this, because that was really traumatic for me...the whole scenario was totally unknown, totally sudden, and like, and it just just totally knocked me...it affected me so much more and the after effects were, lasted so much longer than, than have done for this... that has had a much greater impact on me than, than perhaps this has. Eleanor (71/BC), Interview 1

I'll be honest...the effects of the cancer is, is nowt compared to this ruddy stroke. This, this, this stroke is, is a, it's a crippling thing, bloody thing...God help anybody had a bad one, because I've only had a slight one compared to some people, an'

er, you know, it's, it hasn't ruined me life cos I'm still alive (laughs) but...I can't walk properly and I, I can't write me name. Derek (81/CC), Interview 1

There is a sense among the majority of participants that they belong to a special or fortunate category of people with cancer – a group of people for whom treatment has been relatively straightforward, and who are recovering relatively well. Having a good prognosis was seen by participants as a unique category of cancer experience – a viewpoint summed up most effectively by Tony:

...increasingly I think the cancer world divides into those who through proper early checks, proper screening, proper early catching...it's fairly routine that you'll have survivors who have cancer, recover from it, so breast cancer, er, prostate cancer and a variety of other cancers are eminently treatable, and it's eminently possible to have a pretty good life afterwards. And there are others...[who] aren't in a place where care turns up quickly enough and the treatment's right, for whom it continues to be horrendous. Mmm. But I think there's probably more people more people who have cancer moving to this side of the story than that.

Tony (69/PC), Interview 2

Tony described people with cancers with good prognoses as inhabiting the top of a “funnel” of “degrees of difficulty”, whose treatment enabled them to crawl upwards out of the funnel. Janet described cancer as a “hierarchy”, within which some are better off than others:

She [friend with cancer] said she felt like a fraud when she saw people coming in who are bald!...as I suggested, well, there's a hierarachy...a hierarchy of things.

Janet (70/BC), Interview 2

I'm one of the lucky ones, and I think er, [friend with poor cancer prognosis] put that very much in perspective, because, you know, there's cancer and there's cancer and there's cancer – and he's got cancer, and I got one of these that's fairly straightforward and treatable. Tony (69/PC), Interview 2

Fifteen participants used the word “lucky” to describe their experience of cancer (6BC/5CC/4PC):

I was bloody lucky...I say eighty-five per cent of people get over it. It's the other fifteen per cent I feel sorry for, what don't get over it...I class myself as one of the lucky ones, that I got over it. James (75/CC), Interview 1

I really do feel blessed and fortunate and, you know, who am I to talk about it? Witter on about it?...I've been so lucky, you know. Eleanor (71/BC), Interview 2

It does affect you [when you see others dying of cancer]...I've never done exercise or anything like that and I'm still here, so yeah...I'm a lucky so-and-so, you know. Arthur (77/PC), Interview 2

...one is conscious that a lot of people are a lot more unlucky than we are. We, the group – the prostate group. Stephen (84/PC), Interview 1

Participants who felt lucky included James and Mary, both of whom had previously experienced another type of cancer, the effect of which was to reduce their immediate concern about their recent diagnosis:

I'd just had that [cancer] on me leg, which was painful...And that was painful, this one [breast cancer] wasn't, so I just took it in me stride...with me leg I wanted to die [laughs]...I think you can cope with anything if there's no pain.

Mary (70/BC), Interview 1

First time I found out about my [bladder] cancer I broke down in the hospital, I cried my bloody eyes out like anyone would do...I thought if I can get over one, I can get over this. James (75/CC), Interview 1

The same participants felt that their “lucky” stories of treatment and recovery represented a category of experience that lacks visibility next to more severe cancers, and does not warrant the same attention in the public domain as other life-threatening non-cancer illnesses:

...there are other illnesses that are...equally as dangerous...and I don't think there is so much in place for people who've maybe got heart disease, or something like that...the whole thing with mental health is...it's far more debilitating than cancer, it's as life threatening, and yet the resources aren't there...I'm very,

become very aware of, like... "Oh you've got cancer"...it's like, everybody wants to do things to help you...because it was the big killer. Clare (55/BC), Interview 1

For most, the description of their experience as lucky came easily – one divergent voice was Pete (75/PC), who tried but struggled to make these comparisons work for him:

When you initially get the diagnosis you think, "Well what's the point with bothering with anything?", you know, "Let everything go", blimey...And then, you say, "Come on, get a grip of yourself". You kinda stand back and kick yourself in the back of the pants and say, "What are you wallowing in pity for?", you know, "Good God, there's, people would swap places with you tomorrow – you've got two beautiful grandchildren, a lovely daughter...you're not poverty stricken, you've got a nice home, you run a car, you've got, aside from this you've got perfectly good health, what the hell have you got to lie back and pity yourself for, uh? Wake up!" Pete (75/PC), Interview 1

8.4 Chapter summary

This chapter moved beyond participants' immediate concerns about diagnosis and treatment into the months beyond. Participants' descriptions of informal talk about cancer demonstrated how interactions with other people affected their ways of thinking about their disease. They faced implications that they may die from the episode of disease they were experiencing, or that they may have contributed to the causes of their own cancer. They found these implications difficult to respond to, drawing contrasts with how well they felt, and distancing themselves from the concept of "survivorship" with its connotations of extreme experience. Those with comorbidities saw cancer as secondary to other chronic health problems. Participants were invested in the view that people with good prognoses comprise a distinct category of people living beyond cancer who are not suffering the same level of difficulties as others with more complex manifestations of the disease. The next chapter will focus on the adjustments participants made to adapt to changes in their social worlds, and how they actively sought ways of thinking and behaving that oriented them towards the future.

Chapter 9: Developing assets for recovery

We don't know what's mapped out for us, and you know, you can take a turn at any moment and other things will bring into bearing. So I've always worked on that principle, that you make the best of what there is at that time. And you use, you use whatever resources you've been given – reading, learning, relationships, you know, experiences. And they all come together to help you cope with whatever there is around you.

Eleanor (71/BC), Interview 2

9.1 Introduction

This chapter focuses on how participants drew on the sense-making processes described in Chapter 8 to reorientate themselves in relation to their future. The thoughts about cancer drawn from social interactions began to crystallise into a new outlook. Most participants rejected the idea that cancer is a chronic illness, and that their lives had become fundamentally different in some way as a result of the disease. Nevertheless, they set about *Negotiating personal change* – reaffirming their sense of self and renegotiating relationships and working patterns – and began *Making use of everyday resources* in the home and the local environment in an effort to regain feelings of control, comfort and continuity that had been lost during treatment. The final section of the findings, *Exercising meaning*, explores reflections on mortality, and participants' drive to recover life as it was lived before their diagnosis – or at least to envision moving forwards, having turned the curve thrown by cancer. The findings conclude by considering how participants construct their ability to adopt healthy behaviours, and how they interpreted their experiences during the transition from treatment to follow-up.

9.2 Negotiating personal change

The suggestion that cancer can be life-changing was contested by participants. *Holding on to the self* explores the ambivalence about personal change that emerged from the first and second interview data. Despite an implied resistance to personal change

threading through the majority of participants' accounts, new ways of thinking had required adaptation. Alterations in intimate bonds and family and friendship interactions emerged after treatment, and *Renegotiating relationships* became a necessary task. New perspectives also led to employed participants reflecting on their lifestyles prior to cancer and *Reassessing work*.

9.2.1 Holding on to the self

In the first interviews participants were asked if they felt that they were the same person now as they were before treatment. Of the nineteen participants who gave a detailed answer, eleven answered “yes” and eight answered “no”. Each of these groups contained a mix of working and retired/younger and older participants. In the first interviews, those who felt that they hadn't changed expressed this by reasserting their pre-cancer identity, at times in order to resist being treated differently by others:

I particularly didn't want people at work pussyfooting round me, I wanted them to treat me as normal...for me it was like, I'm me, I'm still me, not just somebody with cancer. A lot of patients probably feel like that. Lesley (43/BC), Interview 1

I'm still me!...I am the same person. And [to husband] it hasn't altered our relationship, has it, me being ill?...it's not made us any closer or anything like that, cos we were like that before weren't we?...nothing's changed.

Fiona (69/CC), Interview 1

For those who had experienced change, prioritising friendships, family time and hobbies had reduced stress and encouraged a more flexible attitude to life. Pete offered a divergent voice – the shock of diagnosis was still settling, and while the same changes were visible as possibilities, they remained at a distance:

[Do you feel like the same person that you were before?] [Pause] No, no. Again pertaining to the cancer, because you know this can happen to you, you're not, you're not the invulnerable person you thought you were. Perhaps you should start pulling yer horns in a bit and not taking so many chances...like climbing on the roof to clean the windows or something... I go, “Hmm, don't ask me what I'm doing next week, next month, I don't know, I don't like to be tied down.” I think

now I shall be a bit more um, "Yeah, go ahead, book me on it, I'll do it"...I think I'll adopt that kind of attitude in six months' time, when I'm a bit more sure of where I am...It is a character change...you're starting to think there's a bit more to life than just plodding along the same little path all the time – you can stick your head above the parapet now and again, take a bit of a chance.

Pete (75/PC), Interview 1

Clare (55/BC), Tony (69/PC), Harriet (72/BC) and Derek (81/CC) were ambivalent about the idea of personal change, and Janet (70/BC), Greg (78/PC) and George (82/CC) felt that life changes were not a result of cancer but of other health and social issues happening alongside. There was a sense in the data that change is more about things other than cancer – about marriage, old age, other illnesses, family difficulties – and that cancer throws these changes into sharper perspective. Janet (carer for her husband, who had suffered a stroke) articulated this clearly:

Well it's like I've entered into, as I say, old age really. It's a sad coincidence about the seventieth year and I feel I've completely, I've completely entered, changed – I'm now in a...totally different phase of life where I always anticipate health problems...I've got to take that on board: I'm getting older. Yeah, total change, yeah, total change in everything...somebody said old age is not for sissies... [husband's] been in this increase in pain over the last year. So yeah, [the cancer has] totally changed things, yes, yeah. Never the same again, yeah.

Janet (70/BC), Interview 1

George talked about his cancer treatment only in passing – far more significant to him was his move to sheltered accommodation, the loss of his wife, and struggling with the memory problems of early dementia:

I don't feel like I used to do, after coming here [sheltered accommodation]. I feel like I've got to look after everything...if I put owt down, I think, where's this come from? I think, d'ah, had this yesterday, what've I put it there for? You know... [laughs]...I thought, I must do one job. Cos I'll be walking through somewhere, you know, and think, oh I remembered to do that now, and I go do it – and at the same time, I forgot the job I gone to do, what I went through for!

George (82/CC), Interview 1

Realisations about the self focused more on the way things had been in the past, and how this had been reinforced, rather than about the changes brought about by cancer:

[Interviewer: Do you feel like the same person now that you were before treatment?] It's a bit "yes" and a bit "no". [pause] I kind of feel like I've grown and that I'm stronger in some ways. I guess it's like, anything that's tested is, becomes stronger, isn't it?...it isn't the testing that makes it stronger, it's what you learn through the testing – that you realise your own strengths, maybe.

Clare (55/BC), Interview 1

In the second interviews, talk about personal change focused more on changes in lifestyle or behaviour than on identity change. Twelve of the seventeen participants in the second interviews said that life had changed, and their statements described an increased willingness to take risks (3BC), a heightened awareness of the value of their close relationships (3BC/2PC), and a lower prioritising of work and voluntary commitments (3BC/1PC). An increase in perceived bravery emerged as participants began to see themselves as stronger and less risk averse:

I don't think I'd let anything beat me now... life's too short to be doing, you know, standing for nonsense... I don't stress about anything anymore. I think everything resolves itself in one way or another...There's more things I want to do now...I feel brave – I know it's silly – but I do feel braver that I can do things, you know, like ride scarey rides. I would never do them, but now I would...Live for the moment, I think that's what you've got to do. Gill (40/BC), Interview 2

There's some things you can't pussyfoot around and you actually have to be, you have to tough it out sometimes...some things that you go through are painful and there aren't answers to it, you have to, yeah [laughs], suck it up a bit!

Clare (55/BC), Interview 2

A stubborn resistance to permanent, all-encompassing change was offered by Gill (40/BC) and Mary (70/BC), who claimed that the concept of being changed by cancer can be used inappropriately to attract an audience. Gill talked about breast cancer patients who claimed the title "cancer warrior" on social media, Mary about persistently holding on to the cancer identity when the experience is over:

Some of the people put on Facebook and that, that they're "cancer warriors"...I'm not happy. [Interviewer: Why does that turn you off?]...I don't think people need to know. You know, we've told people who we wanted to know...me mother was like that, she couldn't stand people fussing – and to have a "cancer warrior" tattooed on you...they're dwelling [on] it, and the attention...they're lapping up on it, and that's not my thing. Gill (40/BC), Interview 2

One of me friends, she...had [cancer] fifteen years ago and she's still "Oh" [miserable] you know, "I got...", you know. And I think that's why [friends who have cancer] ring me instead of her, because I say "Oh you'll be fine – look at me, I'm fine."...Well I think she's just milking it to be quite honest, because after fifteen years, and she hasn't had to go in for any other treatment, I think she's just milking it a little bit you know. Mary (70/BC), Interview 2

Mary and Janet articulated the flip sides of personal change associated with coming through cancer treatment:

I'm a better person. Not a better [person]...I think I'm, feel lucky that, I appreciate things more because I'm seventy, it could have gone the wrong way...I always enjoyed the children playing, but now I enjoy everything better; everything looks greener...I never ever noticed when they cut the grass, but...the smell, you know...It does make yer appreciate things more. Mary (70/BC), Interview 1

I can see what people mean...I'm not poo-pooing it that cancer can make you more appreciative, and I don't think that applies to me, but I can see it could apply to other people – the first time they realised that a tree is a beautiful thing...So cancer is good [in] that it makes you realise, you know, realities and that sort of thing, rather than the beauties of spring, but just simply that, practical realities...some people who had good health...when ill health strikes...they seem to be sort of taken by surprise at an age like, you know, at eighty, when they perhaps can't cope with it. So [cancer is] kind of like an early, you know, "Get your house in order!" Janet (70/BC), Interview 2

9.2.2 Renegotiating relationships

Changes in relationships with others were reported more by breast cancer participants than colorectal and prostate cancer participants – and by more female than male participants. A realisation of the depth or quality of relationships emerged as a consequence of supportive behaviour from friends and family during treatment:

I appreciate things more, appreciate my family, my friends. God, that's, that's, they've been unbelievable, absolutely unbelievable. Laura (46/BC), Interview 1

You can't take people for granted. As in, you need to spend time...the important things are spending time with people, and making the time to spend with people. Clare (55/BC), Interview 1

He drives me nuts sometimes, but we have been married a long time. Erm but he was... he was an incredible...it was like having a hand on your back all the time, you know, it was just there... Eleanor (71/BC), Interview 1

It heightens the awareness of the good relationship I have with my husband, and his strength and steadiness, and all of those things I've said before. Eleanor (71/BC), Interview 2

This appreciation motivates personal change, bringing resolve to alter behaviour to improve significant relationships. Treatment focuses participants on who they are (see section 7.3, *Bringing the self into focus*); adaptation after treatment introduces new ideas about who they can be. Tony explains this, talking about his changing relationship with his wife:

There's bits where you're conscious of the kindness and professionalism of others, at all sorts of levels, whether it's family and friends or work and so on, and that just gives you pause for thought and wanting to...balance out the payback or the recognition or the whatever...maybe balance my demands with everybody else's a bit better...I need to put aside time so that I can take [my wife] to the seaside and walk... I'm now sort of saying...I'll add another level in...where we'll be in six months is that I will be engaging with new bits of the outside world slightly less and [my wife] slightly more and we might meet more in the middle.

Tony (69/PC), Interview 1



Figure 21 *Tony's photograph of a waterfall, taken during a day out walking with his wife.*

An opportunity was given in both first and second interviews to raise the issue of changes in sexual intimacy through asking about changes in close relationships, but in response, most participants focused on emotional rather than physical closeness. Talk about sexuality arose spontaneously with five participants (1BC/4PC), in particular in relation to hormone therapy. Liz (48/BC) felt self-conscious about her altered breast shape after surgery, and experienced menopausal dryness – this had been addressed with hormone ointment which could be applied in advance, but this had removed the spontaneity from sexual contact.

Prostate cancer participants had been prepared for a loss of erectile function by their consultants. Greg (78/PC) and Jack (65/PC), who were both married, were concerned by different issues – Greg at the anatomical changes brought by surgery that shortened the penis and made urination difficult (the loss of erection was a concern, but had been expected), Jack by the effects on sexual intimacy from his wife's perspective rather than his own. By the point of second interview, Jack had begun some enquiries to try to address the issue with medication, but had not seen this as a priority in the year after treatment. For Stephen (81/PC) and Pete (75/PC) – both retired, widowed and single – the effects of hormone treatment were not seen as problematic, but both commented on a loss of sexual charge in their thinking: "it does have a slight psychological effect..." (Stephen, interview 1), "it dulls any appetite you might have in that direction" (Pete, interview 1).

Outside of intimate and family relationships, talk about friendship support arose in only six interviews, all with female participants (5BC/1CC). Five of these participants reflected on difficulties in close friendships as a result of their diagnosis and treatment. For Eleanor (71/BC), this began before treatment – she fears ruining a holiday with girlfriends by revealing her diagnosis, so chooses not to. Later, one of the friends (who had experienced cancer herself) finds out and is extremely upset that Eleanor chose to keep it from her – it ruins the closeness between them for some time. Other female participants reported changes in the dynamics of relationships with close friends during and after treatment:

...some of my closer friends didn't come to see me in the hospital when I thought they would have done, or afterwards...It was really weird, that. That surprised me...They're still supportive in different ways, like I'll meet up with one and we'll go for a meal, and she's given me one of those bags full of presents...So she cares about me...but I found it weird that when I wanted her [during treatment] she wan't there. [quiet, teary] Ellie (64/CC), Interview 2

Where friends remained supportive throughout treatment, or increased their support, close engagement changed as recovery from treatment began. The foundations of this closeness could shift as participants resumed aspects of day-to-day life:

[My best friend] doesn't ask any more... I definitely wouldn't have got through it as well at all without her... I'll never ever be able to thank her enough, but because of the daft situation with the person I was seeing [friend's disapproval of a romantic relationship that resumed after treatment], it got to her and upset her and then it's never been the same. I tried and then I sort of, well I'll leave it... we say hello and things at work and pass the time but it's not the same...She doesn't want to do anything out of work with me or socially now...I don't know what to do about that other than let it go really. Laura (46/BC), Interview 2

Some people that sort of, came out the blue from nowhere when I was ill...have vanished again... I've not seen them...I just found it quite bizarre that people would come round or speak to you when you're just ill, and not at all – I mean, obviously when you're ill people come round more, speak to you more – but you know, not to have that at all...D'you think it's a bit weird? I don't understand

it...Don't know if it's just, people like to help people when they're sick, and that's it. I don't know. Lesley (43/BC), Interview 2

Where close lines of engagement developed with friends during cancer treatment, previous ways of relating could become lost and difficult to recover after treatment came to a close.

9.2.3 Reassessing work

The experience of moulding work around cancer treatment was variable across the eight participants who were working at the time of their diagnosis. Eleanor (71/BC) and Mark (62/CC) were self-employed and in control of their working hours – this involved decision-making about disclosure where reorganising work affected other people. Mark subcontracted work; maintaining his working patterns became increasingly difficult as he struggled with the after effects of internal radiotherapy:

Well I aren't told anybody what's been going on, so; at the end of the day I just said "I'm thinning it out a bit" so...if it's a little job I have other guys who do it, so. It's people I've known for years...I know the job's gonna get done right...So really I've just let it play...see how I feel...some of these customers, I've had some of them twenty/thirty years, so I don't wanna lose me customers just for the sake of not being here. I'm not bothered about the money side of it...I'll get as much from sick as I earn sometimes working down there! [laughs] Mark (62/CC), Interview 1

I obviously didn't tell the people who I work with, although there were some where I had to...because I work regularly [one-to-one] with people, there were times when I had to cancel appointments...because [of the type of work]...it's an authentic and a genuine relationship...I didn't feel I could hide anything.

Eleanor (71/BC), Interview 1

Clare (55/BC), Eleanor and Ellie (64/CC) all worked with clients who were experiencing difficulties. They described their colleagues as the “type” of people who created a working culture of understanding and support:

Well yeah, my line manager, when I was in my blubbering stage, I said “I just can't stand people fussing”, and so she, she just told them all and they were all

really good... I've worked in that office a long time... we've gone through lots of things with different people... marriage breakups and all sorts, so they're all quite supportive... it's like a caring, you know, they sort of deal with that sort of thing... Got people with mental health, drugs, alcohol, all the rest of it – so they know, you know, how to deal with it. Ellie (64/CC), Interview 2

Lesley (43/BC), Laura (46/BC) and Gill (40/BC) had a different experience, having taken an enforced absence from work during which their attitudes towards work shifted. A primary beneficial aspect of work was how it acknowledged people's value, and where participants felt this had lessened (as their skills were seen to diminish), work lost some of its saliency. Where workplaces were perceived as having a fast pace of institutional change, the negotiation of a return to work could be demoralising – diminished skills were highlighted by absence, and could be compounded by problematic physical issues such as fatigue or lymphoedema on returning. The obligation to retrain in basic skills (regardless of previous level of work experience) could reduce job satisfaction as well as confidence.

I felt like a stranger, I didn't feel like I fitted in...I just felt I'd lost all my confidence...Now I feel definitely I'm back to where I was, but it did take, it took months. Laura (46/BC), Interview 2

Lesley felt stigmatised on her return, unable to shake off her illness identity:

...some of the others have said, "Oh I don't, you know, I don't think you should do that yet, Lesley, no, it's early days yet, you've only just come back". But that's like four months after I've gone back! [laughs] Like, I'm fine! It was quite frustrating at times, I think, I was just like, "Look, I just want to get back to normal – um, unless you think I'm not...doing my job properly, or anything like that, and you've got concerns..." ... I think when you first go back people just don't know how, how to deal with it...if you are having a bit of an off day [laughs]...you don't particularly want to admit to it, cos then people: "Ah, you see!" An' it's not particularly through the cancer, it might just be that you've got a bit of a sniffles ...I think you're just trying to prove that not everything's down to the cancer.

Lesley (43/BC), Interview 1

Layla's experience was unusual among participants in this study – having taken time away from work, her length of service in her job (fourteen years) and supportive colleagues maintained her feeling of value and made her reintegration smooth:

I've been able to come back part-time, so I don't have to work full-time anymore, which is a great help...it was fine, it was like I'd never been away...I had to relearn a lot of the things I'd forgotten, which I had to do that when I'd come back off maternity anyway, so it was just; yeah, it was like I'd never been away, you know, they didn't treat me any different...I knew they wouldn't, you know, it's not, they're, they're not the type of people to do that. Layla (44/CC), Interview 1

For those participants who sensed a lessening of their value at work, the solution was to move other things into the centre of life, reflecting a shifting in the position of social worlds. An embracing of home life and leisure led to greater work–life balance, where the foot must come off the gas to allow more leisure time:

I'm not gonna spend as much time at work. [laughs] Yeah, spend more time with my family. See a lot of the time it wasn't money reasons that I had to go out and do these shifts, a lot of it was keeping my skills up, my experience...I wanted to...keep my fingers in lots of pies, and that's not really important any more. Lesley (43/BC), Interview 1

I don't get so stressed about the small stuff. Erm, in the back of my mind when I saw the girls at work the other day I said, "I really don't want get back in there and like get, let work stress me out anymore". I want, I hope it continues at work as well, that I let things go over my head. Laura (46/BC), Interview 1

The concept that work is an anchor point outside of the changes brought by cancer, something that "takes you out of yourself and into other things" (Tony, 69/PC), was acknowledged by both working and retired participants:

...it's how you perceive it, so once you're back in [a] normal routine you don't think "I'm ill still", you know, "I've got cancer" or "I've had cancer"...You're not, you're not homing in on yourself, you're getting on with your life. Ellie (64/CC), Interview 2

Janet described how retirement had robbed her of this strategy for gaining peace of mind by magnifying problems:

...whatever job one's doing, whether it's pleasant or unpleasant, it is a distraction from personal problems... I always knew this would happen, that once you retire personal problems just zoom much larger...nothing much you can do, I don't want to go back to work or anything, but that's one of the boons of work...it is a distraction, and otherwise, like with these four years ahead...any problem would just assume larger proportions. Janet (70/BC), Interview 2

For retired participants Tony (69/PC), Martin (72/PC), Fiona (69/CC) and Arthur (77/PC), involvement with voluntary institutions provided this distraction: these activities made them feel witnessed and valued, and maintained their confidence.

9.3 Making use of everyday resources

Photo elicitation proved to be an appropriate method for encouraging participants to consider their day-to-day resources. Cataloguing the participants' photographic images for the project suggested potential thematic links within the data associated with objects and settings. The participant-generated images included more than fifty photographs of domestic objects, and more than 200 photographs focused on domestic or local settings. The data was returned to and reinterrogated to explore how these resources were used, and whether any overarching codes could be drawn from the associated interview data in connection with material objects and local or domestic environments. The methodological details of this section of the analysis are outlined in Chapter 5.

This section describes the findings connected with this revisiting of the data. It explores the connections participants made between their illness experience and familiar surroundings. It examines how they made use of everyday resources to alleviate or ameliorate the difficulties they encountered during treatment and adaptation to life beyond treatment. The term "resources" is used here to refer to the wide range of material objects – from computers and telephones to items of clothing, furniture and transport – that participants felt were significant to their experience of cancer. One further resource was intimately connected with the

domestic environment – the companionship of animals, which formed an inextricable part of interview talk about resources in the home, and cannot be ignored when considering the nonhuman elements in the data.

Participants harnessed material and structural resources to pursue three objectives: control, comfort and continuity. In exploring these concepts, the section below considers everyday resources in a fluid way: no one object was consistently associated with a single objective – for example, participants' gardens were a source of *comfort*, but could also present physical tasks that helped them to regain feelings of *control*. While boundaries between how objects were used were fluid, discussion of the data is grounded in the way that objects and the settings contributed to strategies for adaptation – for example, by encouraging independence, reflection, achievement, and intuitive feelings of connection within social worlds.

Regaining control examines how participants maintained a feeling of moving forwards, temporarily scaling back their expectations as they accommodated the physical effects of treatment. Feelings of frustration during this process were mitigated by marking short term achievements and making long term plans. *Creating comfort* explores how difficulties could be put to one side by focusing on resources that provided short term ease, and by seeking company or undertaking absorbing activities as a way of filling the mind, displacing uncomfortable thoughts. *Chasing continuity* considers which day-to-day activities helped participants to feel that they were maintaining aspects of life as it was lived before their cancer diagnosis.

All of these processes required effort. The drive to pursue them emerged from feelings of loss – loss of physical capabilities, of psychological ease, of social contact, of “purpose” (Eleanor, 71/BC). Participants felt an urge to address this by creating a sense of forward movement – of progressing their biographical timeline. For those who felt that forward movement was slowed rather than stopped by treatment, getting “back to normality” remained within sight (Lesley, 43/BC). Part of this process was to strike a temporary balance between the short and long term, placing short term ease in the foreground. Alongside this, deliberate long term planning – for example of holidays or of new projects – encouraged momentum. The drive to plan could be lost – a casualty of changing perceptions about physical capabilities, particularly among the older

participants. Efforts to pursue control, comfort and continuity could also be affected by the time-dragging effects of hospital appointment waiting times, by a lack of cooperation from other people, or by an absence of social contact.

9.3.1 Regaining control

Cancer treatment wrested control over day-to-day life from participants by interrupting daily routines and forcing them into new ways of engaging with familiar social worlds and identities. Clare (55/BC) expressed this giving up of control powerfully through a religious metaphor:

It's so corny...but the Twenty-Third Psalm, and walking through the Valley of the Shadow of Death and his rod and his staff being the comfort... I went into that and looked it up... cos it sounds really harsh doesn't it, "The rod"? I mean, it is harsh in a way...When the sheep were going into the pen on a night, the shepherd would put the rod down really low and the sheep had to crawl under it, and the shepherd could inspect them for ticks and everything. And there was a real sense of a humbling effect in being ill and...having to be dependent on the doctors to, to do stuff, and not having control over your life completely, and [pause] yeah, I gained a lot from that. Clare (55/BC), Interview 2

Efforts to regain control focused on *Scaling back needs* and *Learning to live with treatment effects* to keep day-to-day objectives within reach. Participants strived to measure progress by *Marking achievements*, making adjustments to everyday life to accommodate change, and by *Making plans* for the medium or longer term.

9.3.1.1 Scaling back needs

All twenty-six participants experienced their body differently as a consequence of treatment. Surgery, chemotherapy and radiotherapy led to fatigue, experienced as a slowing force. Gaps between clinical appointments had mirrored this change of pace:

The NHS is has its own time framework doesn't it?...its own pace of life...certainly between the operation and the radiotherapy, they would have to wait for my body to recover. But...at the time it just seemed like "Why?"...So there is a real

contrast between all this all this information I have, but the pace...this is just like, [slow clock rhythm] "Tick-tock/tick-tock/it'll-happen/when-it-happens/if-it-happens"...People are saying..."How's things going?"...you have to say, "Well nothing's happening"...There was a pattern there and it was necessary, but if anything caused me frustration, it was that. Eleanor (71/BC), Interview 1

Participants retrospectively associated this sense of slowing with treatment rather than their cancer. This enabled them to frame it as short term, keeping their view of future capabilities (and recovery) intact. The most successful response to the feeling of losing control was to reassess physical capabilities, and scale back expectations to suit this new pace. This included accommodating slow days by focusing on keeping the mind occupied, for example with computer tablets and books:

If you have your iPad you can lay in bed and you can do everything...I used to go to me bed with me iPad [giggles] and me telephone, me tea – I had everything around me that I needed. Gill (40/BC), Interview 1

The slowing of pace helped participants to negotiate the turn in life's pathway – the curve brought about by cancer – as they began to look ahead and move towards setting their pathway straight.

9.3.1.2 Learning to live with treatment effects

Several participants experienced a continual, nagging drive to be active – a frustration associated with the slowing of pace. Their photographs included objects that restored a sense of control over the effects of treatment, allowing them to move forward – to live with the effects, rather than “wait” them out. Arthur (77/PC) expressed delight in one object that restored his ability to make long car journeys:

*[Shows photograph overleaf.] You might not know what one of 'em are?
[Interviewer: A bottle to wee in?] Correct, and that's what it is. And I bought that just after you come the last time...it's in the car...if I get caught short...you can just pull into a layby and relieve yourself...So yeah, that's my secret weapon... You know, "Oh, we're gonna go to Scarborough for the day!" – I'd go "Hmmm". But I've got the bottle. Arthur (77/PC), Interview 2*



Figure 22 *Arthur's bottle.*

Harriet (72/BC), who was a keen squash player and gardener and was irritated by fatigue, kept a kitchen timer in her conservatory as a way of controlling rest periods:

[Shows a photograph of a tomato-shaped kitchen timer]...time is, it's important to me, there's never enough time, so I use that. All our friends know what this is, you know, we used to get a lot of comments about, "So what's the tomato ornament doing in your living room, or your conservatory?"...and I say "It's a kitchen timer". And I think what I've got to do, and I'll just set it for twenty/ twenty-five minutes, three quarters of an hour, or even an hour... [laughs] Cos I don't want to sleep too long. Harriet, Interview 1

For Lesley (43/BC), keeping on top of household routines became a priority to make more time for leisure activities, and her cancer experience provoked a move to a house that was smaller, easier to look after, and less of a financial burden. For Derek (81/CC), the frustration of the after effects of a stroke alongside his cancer compounded his feelings of imprisonment inside the house, but an adjustment to his method of getting outdoors could be accomplished:

I'm just sat here like a bloody cabbage while the while the weather brightens up. I can get it [the car] back anytime I like, but they [the doctors] won't let me, they won't let me drive... what they're saying is me reflexes is not, not what they was. And I think they're right...But it, when the weather picks up I – you see the, this thing I've got [a scooter], it's, the battery'll run for nine hours...you can do a lot in nine hours, it's surprising! Derek, Interview 2

9.3.1.3 Marking achievements

Marking achievements helped participants to recover a sense of forward movement. Domestic tasks could be harnessed for this purpose – Gill (40/BC) displayed her décor, having wallpapered her lounge using one arm while suffering from lymphoedema after treatment; Laura (46/BC) described how she used her sick leave as an opportunity to get on top of things by decluttering her house. Clare (55/BC), Pete (75/PC), Jack (65/PC) and Tony (69/PC) made gardening a priority – Jack photographed his gradual building of a garden path after radiotherapy as a symbol of his physical recovery:

I'm quite proud of me lawn...so I thought I'll, I'll put some steps in so it don't get mushy going up to me new gate. And I took a picture of that one [paving stone] first because after I'd laid that one I had to come in and have a, a long rest because I was shattered. [laughs] This was after the radiotherapy finished... I was really tired at that stage. But then the next day I did the next one, and I thought I'll just do one a day, but the next day I think I did a couple, and then...another one and then two, and then I did two in the morning and two in the afternoon, so I felt as if I was making progress really. Jack (65/PC), Interview 1



Figure 23 Jack photographed the progress of his garden path.

Symbols of achievement displayed within the domestic environment could reassure participants of their abilities or psychological strength in dealing with difficulties – James (75/CC), who had struggled with dyslexia far into his adulthood, showed a photograph of a corner in his lounge where his literacy certificates were displayed:

I did a support tutor [certificate] so I could help young lads with learning difficulties... There was lawyers, probation officers, there was school teachers, all like that, and I come top of the class. That's what I got that [certificate] for...When I sit there and I think about my cancer, I look up, because this is my corner [certificates on wall], everything in there is mine...and I think well if I can do that, I can get over this. And it was a damn site harder to do these sorts of things than it was to worry about your cancer. James (75/CC), Interview 1

Lesley (43/BC) took photographs of her running shoes and medals to demonstrate the gradual return of her fitness to be able to compete in a ten kilometre run; Fiona (69/CC) included a photograph of herself volunteering for a charity and showed an award for this work which “came up at the right time”, helping her to focus on something other than cancer. Making achievements visible and significant sustained participants’ perceptions of being in control of some aspects of life, or regaining control where cancer had threatened to take it away.

9.3.1.4 Making plans

Another way of sustaining a feeling of progress was to make longer term plans for celebrations or for holidays (the symbolic significance of special events is explored in more detail in section 9.4.3) – but this depended upon financial resources. Eleven participants, all of whom mentioned comfortable financial circumstances, talked about the importance of holidays as a way of looking forwards – Harriet (72/BC) and Jack (65/PC) took photographs of foreign holiday destinations they visited with the research camera in hand. Being in a different environment helped to disconnect participants from their cancer patient identity. Layla (44/CC) had a difficult time during treatment, with an uncertain prognosis at the outset. Her response to this was to live day-to-day, but she still made room for looking forwards:

I have to, just, just look forward to, you know, holidays and just, just, I just think my life just goes on and I, I don't expect anything, which I never have, you know. I just live life day by day, just have me scans, hope for, my results are still clear, and just carry on. Layla (44/CC), Interview 1

Pete (75/PC) articulated the change in thinking about planning ahead that cancer treatment had provoked, talking about a holiday to Wales with his daughter, which he photographed multiple times for his interview:

I've become a bit of a recluse over the last four years, and I enjoyed that holiday with me daughter and grandchildren, and she's already making noises about going away somewhere next year...I think now I shall be a bit more um, "Yeah, go ahead, book me on it". Pete (75/PC), Interview 1

Planning for the future was an effective strategy for the majority, but not all participants felt safe to do so. Janet (70/BC) felt that longer term plans to travel had been compromised by ageing and the possibility of the cancer returning. David's (80/CC) possibilities for foreign travel to visit his son were affected by ageing and his wife's ill health. George's (82/CC) social isolation, in combination with the beginnings of memory problems from dementia, set him adrift from the future: he lived day-to-day. George's episode of cancer was not central to his interview talk, he seemed to forget his treatment at many points in the interview, talking instead about his extreme sadness over the loss of his wife and of the loss of the independence he had enjoyed as a working man. These participants found the biographical back-and-forth – moving between their past, present and future in their thoughts – difficult to negotiate.

9.3.2 Creating comfort

Searching for small pleasures could ease everyday difficulties by bringing possibilities for short term enjoyment into sharper focus. Pleasure and relaxation came from familiar objects, from *Staying grounded* in local environments, from *Enjoying animal companionship*, and from finding ways of *Clearing the mind* of the psychological discomforts that bubbled up in the wake of diagnosis.

9.3.2.1 Searching for small pleasures

The search for small pleasures could be satisfied by familiar objects and experiences, items that were often presented as symbols of the self. The salience of these became clear through participants' photographs and their investment in explaining why they were taken. Significant objects could be as simple as a personal tea mug (Gill, 40/BC,

photographed her “Little Miss Giggles” mug) or the same customised cup of coffee (Liz, 48/BC). Among Liz’s photographs of her “everyday things” was a cup containing a latte with a chocolate powder heart on top (“This is my bit of luxury”). Inexpensive material objects made by others in response to participants’ diagnoses were displayed in the home as physical manifestations of support or love. Derek (81/CC) and Eleanor (71/BC) took photographs of their most symbolic objects.

Derek: That flower is made by an Indian postmistress when I was in hospital. It's made of paper...It took her about two minutes to make.

Wife: ...There's a queue of people waiting for their pensions and she's at playing with this, you know, and I'm stood, and I'm saying to her “There's a queue here”. “Oh they can wait, they can wait, it's for Derek, it's for Derek!”

Derek (81/CC), Interview 1

The last of the photographs is this [heart-shaped lavender] cushion. This cushion arrived by post, and highly unannounced...from one of the people who picked up my work... She had had breast cancer...she sent this through the post and said, “When I was having my treatment, somebody made one of these for me, and it’s great to tuck under your armpit when you go to bed, so that you’ve got some sort of protection between you and the breast. And so I thought you might like it and I’m thinking about you”...But that [photo] represents not just her gift...but also represents all the, my other friends who’ve sent letters and cards and flowers, and have really, sort of on a very regular basis, sort of checked up on me.

Eleanor (71/BC), Interview 1

Favourite domestic spaces also provided comfort. Harriet (72/BC) and Martin (72/PC) took photographs of their conservatories, Fiona of her large outdoor shed (her “retreat”), which had been converted into a sitting area. Associated interview talk explored the therapeutic nature of domestic spaces.

That’s our conservatory...Now we spend a lot of time in there actually because we like the wildlife and I think it’s very therapeutic looking out here...it looks as though you’re in the middle of the country, don’t it, really?

Martin (72/PC), Interview 1

Derek (81/CC), Gill (40/BC) and Fiona (69/CC) photographed their lounges, Laura (46/BC) and Liz (48/BC) their bedrooms. Jack (65/PC) and Derek (81/CC) each claimed ownership of a comfortable chair in their lounge – Derek photographed “his” chair, Gill (40/BC) photographed her sofa:

My sofa did get a lot of hammer...some days I didn't want to stay in bed and [husband] used to help me get up and I used to be laid on here... [Interviewer: So that was your alternative place?] Yes. You know settees are very good – very good for recovering. Gill (40/BC), Interview 1

The majority of participants' photographs were focused on domestic settings (see Table 5, p103) – the familiarity of these surroundings, and their association with personal choice, affirmed participants' sense of self.

9.3.2.2 Staying grounded

Fourteen participants were born in the Northern city where this study took place – Derek (81/CC) and Mary (70/BC) had lived on the same local estates since childhood. Four further participants had spent most of their working life in the town, and it had been home to them for two decades or more. Many talked about how the local environment (in particular the sight of a well known local landmark) made them feel grounded.

I've been on this estate really since I was seventeen, so, and I know everybody. I mean I sit on me bench and people...cars are waving and that...I think if I had to move off it, this estate, I would be lost, I couldn't live anywhere else but here.

Mary (70/BC), Interview 2

[Showing photograph overleaf] When you look down my lane and you get to my house, it's just open fields and countryside...I remember coming out of hospital... and seeing that view, and I just, breathing a sigh, sigh of relief [upset]. It was, it was [pause] it was quite an odd feeling...it's such a beautiful view... I didn't know whether I was gonna come home, and it – seeing that was, yeah, amazing.

Layla (44/CC), Interview 1



Figure 24 *Layla's rural view.*

Stephen (84/PC) and Pete (75/PC) had both moved to the city from elsewhere to be nearer to adult children and offer support for grandchildren. Stephen had moved into a rural village with a good sense of community – he enjoyed a good social life, and was open about his diagnosis. Pete, in contrast, expressed a sense of unfamiliarity and discomfort (his experience of isolation is explored in section 8.2.5, above). Gill (40/BC) was born in the city, and had worked at the same firm for many years – during her time off sick, she deliberately cultivated a group of friends from work who met at her house once a week to watch a film and eat hot dogs together. Jack (65/PC) also continued to meet with the same group of local friends regularly. The company of others kept them buoyant through treatment and recovery.

9.3.2.3 Enjoying animal companionship

Human relationships were not the only prominent source of good quality support represented in the data: a special position was reserved for domestic pets. Animals brought “company and bit of comfort” (Ellie, 64/CC) and participants made a direct connection between pets and health and wellbeing – for example, dogs provided motivation to get out of the house and exercise. Nine participants owned animals – seven owned dogs, one dog-owner also owned a budgie, and two participants owned cats. All nine participants photographed their pets and talked about their significance.

She's such a lovely dog, it's unbelievable, she just sits, she never barks, she's happy, she's, I mean she was laid next to me bed but every morning I woke up she

was next to me on the bed. [laughter] And anybody that passed, you know, they couldn't believe how good she was...and it was nice to have a bitta company that didn't talk yer head off! Mary (70/BC), Interview 1

My dogs...they're always there for you, and bless 'em, if, if you're upset I think dogs sense it as well, don't they? And especially the big un, she, when I come out of hospital that day, she come over and, she's the American bulldog, and she sat in front of me and she sort of like, had a bit of a tearful moment like you do, and she come over she sat like, an' her eyes were going, and her paw came up on my lap as if to say, "Oh mum, don't cry"...I love 'em, bless 'em, they're always there for you. Company as well, isn't it? Liz (48/BC) Interview 1

I go out endlessly walking. I mean I'm quite a big believer that, you know, you've got to keep exercising...I always take him out mornings, lunchtime, evening. Martin (72/PC), Interview 1

Mark (62/CC) and Gill (40/BC) felt that their pets could intuitively sense cancer – a skill that elevated feelings of emotional closeness:

Before I was diagnosed she kept coming in she kept laying on me, and I kept saying to [husband], "Why is she always laying on my boob?" And it was like she must have known. Yeah, she's clever...She used to come and lay with me when I was sick...she wouldn't leave me. Even when I come downstairs she'd come and lay with me...and she doesn't do it now. She doesn't. Gill (40/BC), Interview 1

Mark (62/CC) took multiple photographs of his dog, which he felt was the most significant part of his life in relation to his cancer, and summarised the feelings of other participants about their companionship:

...even if you don't feel like going out you've still got to take 'em out for a walk...you can't go anywhere far away from the toilet when you first get it, and you feel sick and whatever, and you, you get down in the dumps a bit with it. But there you go, that's life, innit? ...I got her, cos I thought well it's gonna make me do something, you know, even if it's only just take her out for a walk and whatnot – and believe me, if she wants to go out for a walk, she wants to go out, and that's it! [laughter] Mark (62/CC), Interview 1

9.3.2.4 Clearing the mind

Another avenue for comfort included the deliberate strategy of displacing difficult thoughts by undertaking activities that absorbed or cleared the mind. This happened in reaction to uncomfortable thoughts provoked by diagnosis (“What good’ll you do by dwelling on it and being down? You can’t do anything”, Lesley, 43/BC, interview 1). Stephen (84/PC), who chose not to take photographs, took me to see his library before I left – eleven participants spontaneously talked about reading as “another comfort” (Ellie, 64/CC), as a way of escaping (Clare, 55/BC), chilling out (Eleanor, 71/BC), changing pace (Fiona, 69/CC) and resting (James, 75/CC). Maura (81/BC) talked poignantly about the significance of the loss of her mobile library and the difficulties of carrying heavy books home from the city’s central library. For Lesley (43/BC), reading was a temporary activity when she underwent chemotherapy – her reading stopped when treatment came to an end.

Books are the coping with the – cos I’m such a busy person, always on the go, and for me, you know, like the days when I couldn’t go out, or I couldn’t do anything, it was like...I’m not really a TV person, so, turned to the books...[Interviewer: So what was it about having your head buried in a book that helped?] Switching off ...not dwelling on things, I think. Yeah. It’s just a coping mechanism, isn’t it?

Lesley (43/BC), Interview 1

For male participants in particular, hobbies were a meditative activity:

You’re sitting there, you’re painting, and you’ll be miles away, you’re in the picture itself like, and you’re thinking, you know, you’re not saying to yourself, oh what happens if this doesn’t go right? And it goes out the back, right out your mind, all you’re thinking about is what you got in front of you.

James (75/CC), Interview 1

...you get doing something [model-making in the shed] and you get interested in it, you know...just going to do that bit more...you can get hooked on certain things that you’re doing, that you’re enjoying, and you do just lose track of time you know, do this and do a bit more, you know. Arthur (77/PC), Interview 1



Figure 25 *Ellie's car – an indispensable aid to her painting hobby.*

For breast and colorectal cancer participants in particular, treatment had disrupted regular hobby activities, stealing the sense of contentment or displacement they brought. Ellie (64/CC) pointed out how possessions and activities are linked, and how chains of cause and effect build up around them. Her main hobby was painting, based on photographs of scenery taken on trips into the countryside. When she couldn't drive after surgery, her painting was interrupted:

...couldn't drive for six weeks [laughs] that was like having my hands and legs chopped off (laughs) so, cos my car is, leads on to my painting, which is my main hobby. I, in the summer I go out in my car and take photographs, umpteen albums full of photographs that I use [laughs] as...you know, to give me something, sources for me to paint from. Ellie (64/CC), Interview 1

For Derek (81/CC), fishing was a key pastime – but this link with his old self and the outdoors was lost when his stroke robbed him of his physical capabilities, and a thief stole his fishing equipment:

My interest was fishing...you, you get a bug for it. Mine started when I was about seven or eight, tiddlering with a cotton and a, a bamboo cane and tying a worm on 'em and then tiddlering in park, or anywhere else ...then it snowballed... [Interviewer: So what stops you going fishing now?] Two things mainly – this ruddy stroke, and I, some dirty bugger pinched all me gear.

Derek (81/CC), Interview 1

The displacement of negative thoughts could also be achieved without material objects – reflective thinking in itself was described as a comfort. For Clare (55/BC), opportunities for “quiet times and yeah, reflection” gave her a sense of trust in what would happen to her. Calm spaces in the local environment were discovered in the weeks after treatment – places where this type of thinking could be exercised. These could be spiritual or a domestic spaces, or a particular outdoor destination or “haunt” (Martin, 72/PC) visited more frequently than usual during the cancer experience.

I work in a church building...they'd set up something they'd called an urban retreat room...I'd go into work and go to this...Several days a week, they had like a quiet time of sort of contemplative prayer? So you just go for half an hour... some of the prayer techniques...I found really useful...to calm myself down.

Clare (55/BC), Interview 1

I took [a photo of a local bridge and beauty spot] because, oh, I used to drive down there – take the kids to [school]... and then just drive there or sit there and have a coffee or just walk on my own and think. I can't even tell you what I thought about just.... but that was where I went a lot of times, went along a lot of times to just sit. This is after diagnosis. [Interviewer: It wasn't something you did before?] No, no...I wan't gonna jump! Cos that's what [friend] said, “You're not jumping, are ya?” [laughs] “You're not gonna jump off the bridge?”...I just wanted to hide away. Laura (46/BC), Interview 1

Few participants were active members of a church – only five spoke about religion, and it was difficult to find a placeholder for spirituality within the analytic framework of the study. It was clear that its role was fundamental and experiential, and that considering it under a stand-alone descriptive code would do little to clarify its role in adaptation. Stephen (84/PC) helped by articulating the role of spirituality as a metaphor for psychological comfort, suggesting its inclusion in this section of the findings:

The god I believe in is that spark of altruism that suddenly emerges out of nowhere among, you know, in in, even in me occasionally. In the most miserable of people, there's that, er, spark of the divine, which is all I think I really believe in. That's my god...in the last years I've lost that...Christianity's supposed to give you a [pause] a comfort, you know...it's partly the habit of a lifetime, it's partly

that I like the company of people who are interested in morality...religious practice is only a metaphor for something else...custom...an affirmation of feeling. Stephen (84/PC), Interview 2

Photographs taken by Arthur (77/PC) and Clare (55/BC) included pictures of the churches they attended, which they talked about as places of comfort. For both, the church offered fellowship. Clare photographed the resource that provided a constant reminder of this fellowship – her mobile phone:

I'm gonna go, look at texts people sent me...because I'm a member of a church had a lot of people who were praying for me and a lot of people...let me know that they were praying for me, that was helpful...texts aren't intrusive, are they? You can look at them when you want to... my own church and people from the church where I work an'...yeah, I had lots of people who'd say... "If you do need some time, I'm here". And all though I maybe didn't use them, knowing that they were there [pause] was wonderful. Clare (55/BC), Interview 1

They all want to know how you are doing...they're concerned about me...I keep getting messages that they was all praying for me...people were thinking of you, they knew you'd got problems, which I found helpful...the church has been good to me. Arthur (77/PC), Interview 2

Gill (40/BC) expressed the loss of comfort that accompanied her loss of religious beliefs – a sense of uncertainty and fatalism:

I don't know now, I don't know. I mean, I wear my cross. I don't know, I don't know. I don't think there is anywhere else to go, I think I've realised that...I think everything happens for a reason and you can't stop it. Whatever's gonna happen is gonna happen...All my old beliefs I don't do any more. Gill (40/BC), Interview 2

In Laura's first interview, the same uncertainty came alongside an expression of need – a bargaining or negotiating, resolving in the psychological comfort of making a deal that enabled her to imagine a long life ahead:

I still don't know what I believe about when we die – I think when we die there's nothing – whether there's God, I don't know. But you do talk to God in times like

last year, and I remember thinking just, right, I just want twenty-five more years, give me twenty-five more years – bargaining...the kids will be well older then, but then I'll know they're all right...I don't know who I'm talking to in my head [laughs], but there's somebody...I think that's it...when we die, that's it, that's your lot, that's it, just gone. But er, yeah, it's funny at certain times you talk to this being or certain person...It's funny when you need them, isn't it?

Laura (46/BC), Interview 1

9.3.3 Chasing continuity

For all participants, illness disrupted taken-for-granted continuities in life such as well established routines and relationships. *Keeping up roles and routines* was particularly difficult for breast and colorectal cancer participants, who experienced fatigue and other effects as a result of treatment. Retired participants, in particular Janet (70/BC), Maura (81/BC) and Greg (78/PC), considered ageing as a process that compromised or worked against this preservation. Interview talk considered how this was let go, either willingly or with resistance. Participants made an effort to iron out the creases that cancer pushed up in their biographical timeline, working to preserve the *status quo* wherever they could. This was not easy – *Keeping up appearances* was difficult in the time directly after treatment.

Chasing continuity at a domestic level was resourced by finding ways of *Staying connected* using objects such as computers and iPads. For participants who had families, the social world of the family became an important source of connectedness. This was partly enacted through celebratory events (explored further in *Marking the timeline*, section 9.4.3), but at a more personal level, through the active memorialisation of family members who had passed away. For male participants in particular, connections with broader timelines outside of the personal helped to maintain a more global notion of continuity – connection with the outside world via television or the internet kept them anchored as they encountered fluctuation and change in their own lives. Participants were actively *Seeking security* in pursuing pre-established lifestyles, but resuming taken-for-granted activities could be threatened by the onset of ageing, or by a lack of financial resources.

9.3.3.1 Keeping up roles and routines

The majority of participants talked about efforts to resume everyday domestic responsibilities after treatment – photographs included images of activities such as ironing, baking, gardening and dog walking. Janet (70/BC) took a photograph of a pile of ironing as a metaphor for how cancer affected her thoughts and feelings:

I actually love ironing... I love it [laughter]...I'm quite heartbroken that I often don't have time or energy for it, cos nothing nicer...I always fold things as though they were newly bought, you know. I think my mother got me into it, she used to work in a shop...mother taught me this, how to fold things professionally...And this [photo of unironed clothes] represents the chaos. And in fact it's like that at the moment, the chaos of unironed stuff. Janet (70/BC), Interview 1



Figure 26 Janet's unironed "chaos" (left), and the re-establishment of order (right).

The ability to preserve physical capabilities in order to continue family routines and responsibilities is a lynchpin: it keeps the symbiotic network of the family intact. For other family members, a display of compromised physical abilities on the part of the family member with cancer is a measure of change that can cause alarm or distress. For the patient, the maintenance of family roles is a reason to set goals – to form a conception of a normal level of activity and work towards displaying this as part of recovery.

...me daughter was helping me with tea, and I was cutting up a butternut squash [laughs]. I only cut twice, an' I went, "I'm going to have to sit down!", and I came out in a sweat, an' I was shaking, I was so fatigued – I came down here and I shut

my eyes. It upset her. Because it made her realise how ill I was. But I was trying to get on with things, and trying to look normal, and she was, she was quite tearful.
Lesley (43/BC), Interview 1

What gets me partly now, is, I can't take the dog for walks like I used to, once. Cos I was always tekkin' the dog for walks, but now [daughter] does it.
Will (75/CC), Interview 1

Recovering day-to-day roles and routines, and marking the physical achievements implicit in their accomplishment, was not straightforward for all participants. Arthur (77/PC) and Will (75/CC) described how this depended upon the cooperation of others:

Six of us...we used to meet every Thursday afternoon up at [a historic railway venue]...we'd go in there, have a cup of coffee and a natter, we put the world to right...when I was having the treatment of course, that was stopped...they decided they wasn't going to do it...I said, "OK, that's up to you, but you're being a bit silly". Arthur (77/PC), Interview 1

But the thing is like, it's probably for my benefit, but me wife and daughter won't let me do a lot of things – 'cause I, I like to do a little bit, but I mean just now today, me wife's done all the back way bit of gardening, right down, and I was looking at it and I was thinking "I'd like to do that" [laughs]...Well they won't let me...I can't do the hoovering...and like carrying shopping or owt, they won't let me do that...I can carry one bag at least, I can do that, but [laughs] [daughter], she plays up hell, she says "I've told you, no". And I thought, "You've got to let me try it, at least". Will (75/CC), Interview 2

Participants who had been through prostate cancer treatment experienced less intrusive after effects, and managed to maintain previous routines to a greater extent – all though this still involved learning to function despite symptoms:

I go ten pin bowling every Tuesday... Some of the tablets I take can make yer dizzy if you get up too quick...so I got quite dizzy during [laughs] during it, and also you have the hot sweats...you get very warm bowling as well. But I'm in this Seniors' League, so I go every Tuesday, and, and I didn't miss any...So that's why I took a picture. Jack (65/PC), Interview 1

9.3.3.2 Keeping up appearances

Female participants Lesley (43/BC), Clare (55/BC), Gill (40/BC), Mary (70/BC), Laura (46/BC), Liz (48/BC) and Ellie (64/CC) talked about their efforts to maintain or recreate their previous physical appearance to others after treatment. Eleanor (71/BC) chose not to have chemotherapy (after weighing up her oncologist's recommendations), because her hair was such a key part of her physical identity:

Do I need chemotherapy?...Will my hair fall out? I'm a vain creature, and my hair has always been a defining part of who I am...I have this distinctive hair, so you know, it's sort of always been part of me, and the thought of being without it was like, "Phffffff!", you know... my husband and I...we sat down and we had a chat and we decided that I wouldn't go for the chemotherapy.

Eleanor (71/BC), Interview 1

Gill (40/BC) did not maintain the same body shape in the months after surgery, and felt the loss keenly when she dressed for a party:

...they was having a black tie evening dress, and I got my evening dress, I got it last year, and I couldn't get the zip up over my lump, and I was like, oh. Even just, just silly little things like that, you think, oh, I miss it. Gill (40/BC), Interview 2

For these participants, keeping up appearances as if cancer had not had an effect was an aim that remained fundamental, beneath other more transitory feelings:

[Showing a photo of the Skype symbol, talking about video phone calls] Skype is a good one cos my sisters live away...they could see me...that was probably me reassuring them that, "Look, I'm OK – I look OK", you know. If I can show them that I look OK, you know, they, they felt more confident, which in turn made me feel better, you know. Lesley (48/BC), Interview 1

It's just the shower and trying to do your hair...to actually do your hair to make it look nice... to do it every morning was hard work [laughs]. I didn't want to go out looking like I do now! [laughs] Mary (70/BC), Interview 2

[Showing a photograph of surgical stockings in the bin] It was wonderful to get rid of my surgical stockings [laughs]...my legs were all dry and scaly. So then I

could put these nice sexy tights on with a dress...Oh! I should have put my nice shoes, smart shoes, that was what I was gonna do: put my dress on, take a picture of me all glammed up rather than with those horrible stockings that were falling to bits and going all disgusting! Ellie (64/CC), Interview 1

Displaying the ability and energy to present the familiar self to other people as a sign of recovery sometimes covered up the work of adaptation and adjustment happening behind the scenes.

9.3.3.3 Staying connected

For female participants, social media and Skype were a means of interaction and connection with other people – for the male participants, tapping in to a more global sense of continuity was also a part of recovery. This broader perspective was exercised through a variety of more distant social worlds via computers, computer tablets, social media and shared hobbies.

I'm like a bear with a sore head if I haven't got me computer. Cos that's my outlook on the world, is a computer, get to know what's happening all over the world...new stuff that's coming in and things and new ideas. I saw this thing about the cancer, prostate cancer, "Phoo, I'll have a look at that" you know. I like to, I like to be up in the news and know what's on...Even in the workshop I had a, depending on what I'm doing, it's no machinery involved, I have the radio on... I like to know what's happening in the world...So yeah. That's my life.

Arthur (77/PC), Interview 2

Participants' descriptions of family memories also contributed to the sense that they were focusing on the wider continuities that weave through life – the social continuity of which they were a part. Tony (69/PC) talked about his attempts to recreate the happiness of his childhood in recent years – while efforts to help his son's business caused strain during his treatment, many of his photographs documented the significance of these efforts towards continuity through the generations:

If you sort of think about it in a psychological way, I guess, because I was completely ignorant of what it meant, all those seven farms [where he lived as a

young child]... were glorious playgrounds and very happy places. Hence all the chickens and... possibly something to do with [son and his rural business] – there's all sorts of things that are happening which might be associated [laughs] in some way with the best bits of childhood, I guess. Tony (69/PC), Interview 2

Maura (81/BC) talked about the importance of continuity in reference to a family dinner set that had been inherited by her grandson, who did not perceive it in the same way:

...[grandson]'s got rid of everything that's associated with his parents. We, I had words the other day...I said, "Don't throw that dinner service – I bought that for your mum and dad for one of the anniversaries"... He said, "It's old fashioned".

Maura (81/BC), Interview 1

One domestic resource kept family continuity firmly in mind – objects that were not part of the photography brief for the project, but which the visual methodology opened up as a legitimate source of dialogue: photographs displayed on sideboards. Maura (81/BC), Stephen (84/PC), George (82/CC) and Greg (78/PC) did not take photographs for the project, but showed or referred to photographs in the room in which they were interviewed as we talked.

[Family members] said we want you to look at this, open this Christmas present...I opened it, and there was a photograph – that's me brother, where he's buried [indicates framed photo on sideboard] – and it said, it said on it, there was two lovely photographs he'd got off the internet with British Legion, 'n' said, "We are taking you to France for three days, so you can see his grave and take him some flowers". An' that's what we did. Maura (81/BC), Interview 1

This strand of Maura's interview demonstrates how remembering close, contemporary or younger family members who had been lost maintained participants' feelings of connection during the uncertainties of diagnosis and treatment. It helped to place cancer treatment into a wider perspective in the same way as marking celebratory events (see section 9.4.3). Pete (75/PC) supported this with a photograph produced for the study (overleaf), showing a tree that he had chosen as a memorial for his son:

That's where me son's ashes are scattered...I've told me daughter that when my time comes – I have me wife's ashes in the house – when my time comes I want our ashes taken and sprinkled there... we're all together then...This [photograph] more or less identifies the exact spot, yeah...I've cut his initials, his name into the tree, you can't see any detail on there, but I cut [son's] name into, into the tree there. Pete (75/PC), Interview 1



Figure 27 *Pete's photograph of his son's memorial tree.*

9.3.3.4 Seeking security

Participants described two factors that dampened or disrupted their motivation to work towards continuity: ageing and financial security. For retired participants, cancer treatment happened alongside concerns about the ageing body. The temptation to foreclose on attempts to “get back to normal” was stronger in older participants – “normality” had become a state of constant flux:

...this year I'm going to be seventy-eight...me time's running out because of me age, has nothing to do with what I [the cancer], you know! So I think well, is it worth starting this [model-building project]?...cos they're complicated... Years ago we went to see the Falkirk Wheel, something I always wanted to see...Want to make a model of that. But would I ever get it finished?...I'm coming to the

conclusion, if I do and I don't get it finished, they'll just throw it in the skip with the rest of my things...I remember a great nephew years ago...the chap next door to where they lived died, and he says they took his things away in a plastic bag – that was his life. Yeah, when you think about it, it is. You know. So yeah, so whatever I do next, I don't know. Arthur (77/PC), Interview 2

I used to think to myself, well after [husband's] gone I'll be able to go to the Grand Canyon – but no, probably won't happen, you know. Whereas it's often an assumption, as I said before my oldest friend once said in the company of, my husband was there, she said – when she's married to a friend – she said "When he's dead oh I'll come back and live in England, and..." [laughs] you know...that sort of assumption that women have. But yeah it's made me, it's changed totally...I mean the 20 years [of single life] – maybe it won't be, you know. Janet (70/BC), Interview 2

I don't want to do anything – I've done it, I've got the t-shirt and everything. David (80/CC), Interview 1

In contrast, many of the older participants were financially secure in a way that allowed an element of continuity that younger participants did not enjoy:

Money dun't mean anything any more. It doesn't...I'm like 75 now...if everything's all right with the family, that's the main...I don't mind, you know like, giving money out, or owt, as long as it's for the right reasons. Will (75/CC), Interview 1

The house is paid for, it's, I've never had, I've never had a mortgage so it don't really affect us that way. Mark (62/CC), Interview 1

The preservation of financial security allowed lifestyles enjoyed prior to treatment to continue afterwards, dependent on physical capabilities. Financial arrangements during sick leave varied from one participant to another. All but one of the retired participants benefited from works pensions and property ownership, and deliberately contrasted their situation with that of younger generations – with the caveat that circumstances could change:

We'd paid our mortgage off there, you know, in that house we were in... everything were free, you know! ...it's nearly six hundred pounds a month now to live here alone [as a widower in sheltered housing]. George (82/CC), Interview 1

Working participants' financial arrangements with employers varied – some moved to half pay, one participant still received full pay. Only one participant, Laura (46/BC, a single mother), felt insecure with her financial situation – other working participants were supported by partners, or were financially secure without work.

...the last time I spoke to my mortgage company was Christmas and they said "Right, we'll give you six months"...I've still not paid off what I owed them the two months that I didn't pay because of it, and I've got to ring them this month actually and say can we renegotiate...I'm dreading the call...I'll have to go through it all again, and they'll say to me, "Oh why did you?"...[default on your mortgage]...they won't look at their records, they'll say "Why?" and "Why did you miss your payments?" Then I'll go through it all again...I'll save that for next week, when I've got an hour to spare. Laura (46/BC), Interview 2

For some, the prospect of living longer brought money worries, but for others, the experience of cancer made them feel less concerned:

I'm a little bit scared of spending money and I think if, if...I need to have enough money or we need to have enough money to live...into our nineties – hopefully, if I'm as healthy as I am now, and I don't consider myself to be unhealthy just because I've, I've had this problem. No, I feel guilty I think, you know, I don't consider that I've got a problem you know it's a just an historical part of my life which hopefully I can forget about after I've been to see [the consultant] in May. Harriet (72/BC), Interview 1

I don't tend to put stuff off now. And I'll, I'll, I'll spend a bit more than I used to spend. Before I used to be careful about what I spent, but now I think, well I might as well! [laughs]...I'm a bit more inclined to treat myself than I was previously. Jack (65/PC), Interview 2

9.4 Exercising meaning

This section explores how participants' meaning-making, described in *Filtering cancer talk* (section 8.3.1, above), encouraged new ways of thinking. *Facing mortality* describes reflections on the possibility of death, which became an exercise more associated with a renewed sense of humanity than with the concept of cancer as a terminal disease. Alongside this, *Resisting chronicity* was a way of maintaining hope for returning to life as it was before diagnosis. Future orientation was facilitated by *Marking the timeline* – maintaining an investment in celebratory events that brought a sense of belonging, and helped participants to envisage goals and plan the extension of their biographies. *Making decisions about healthy behaviour* was circumscribed by pre-existing health behaviours, comorbidities, and the perception of bodily changes as an inevitable part of ageing. Experiences of follow-up among participants were variable – many felt that their health unexpectedly became their own responsibility by default at the end of treatment: *Looking for closure* had been an unsatisfactory process.

9.4.1 Facing mortality

A new or renewed sense of mortality motivated a desire to do things in the here-and-now for the majority of participants – they had developed a keener realisation that at some point, possibly quite suddenly, they might be cut off from tomorrow. Participants construed mortality as something to do with being human, rather than with being unwell – that cancer simply brings it to attention:

What have I learned?...It's reminded me of mortality, but that's not something that I needed the cancer to tell me, it's something that lives with me a lot, is my mortality. That's a whole different piece of research. Eleanor (71/BC), Interview 2

I think you appreciate life more because you know, at the end of the day, you've always known, the day you're born you'll soon start thinking, you know, eventually you're going to die, cos that's the system. Arthur (77/PC), Interview 1

I still think that, yeah, there's a chance I could get cancer, but yeah, there's still a chance I have a heart attack or a stroke [laughs] you know. I don't feel, wow, I

must, must make on with my life, you know...I don't think it's particularly been a life changing thing. Ellie (64/CC), Interview 1

I don't think [the cancer has] made any difference to me at all...it offers to me the prospect of one form of dying...I've been conscious of the onset of death for forty years...I think perhaps I ought not to have said that, because your original certainly not banal question [Has cancer changed you?] eh provoked the original answer, "No, it's made no difference at all", and I still think that's true. But groping for possibles? Stephen (84/PC), Interview 1

An increase in impatience is a side effect of this sense of mortality – but this was seen more as a change of perspective than a fundamental shift inside the self.

I'm more impatient! [laughs] Everything's got to be "Now! No not, you know, not later on – let's do it now!" Don't put, I don't put things off. Mmm...nobody's said I've changed... nobody's said I'm a different person. And I don't feel different apart from [pause] impatient. Lesley (43/BC), Interview 1

Tony summed up the perspective of the majority of participants by characterising the experience of potentially curative treatment as a “steady curve” rather than a sudden moment at which they face death:

For a lot of people it just goes on a very steady curve and for some people it turns and that's when it becomes a problem. A lot of people just fall off the end...most, most, most of us would have died between sixty and seventy, historically, and now we don't, so I think there's all sort of stuff like that. Wake up in the morning and count the bits and see what's fallen off, you know! [laughs] Yeah.

Tony (69/PC), Interview 2

Retired participants took a more fatalistic view on the possibilities of dying than younger participants. Laura (46/BC) found diagnosis a shock, and rationalisation about mortality happened as treatment progressed:

*If I'd had somebody say this to me this time a year ago, whatever: "There's light at the end of the tunnel"...I'd 've probably said, "F**k off! What do you mean, there's light at the end of the tunnel?"...But there is, there is. But how you'd say*

that without making somebody cringe and think “Get stuffed! I don’t wanna know!”... It’s a hard one... see I thought, I thought, God that’s it, I’m gonna die. That’s what my initial thought was. Totally irrational. It’s cancer, I’m gonna die. But it doesn’t mean that. Yeah I’m gonna die eventually, but we all are, aren’t we? Laura (46/BC), Interview 2

Retired participants could feel the same worry, but were more likely to express a fatalistic attitude:

The experience of finding out that you’ve got cancer...I think everybody is the same you get depressed, you know, how long have I got?...you got to set your mind in...but some days you just don’t get that feeling, sort of thing, and you do get depressed...I think it’s what your attitude to life – all right, you’ve got cancer and you think, oh Christ almighty, you know, but then you think about, you know, you’ve got to die sometime. Arthur (77/PC), Interview 1

I aren’t fooling myself into thinking it... life’s perfect. It isn’t. it’s not, it in’t...it dun’t bother me... I mean, [daughter] thinks it’s... I’m getting negative thoughts and that and I... I aren’t, it’s just, it’s just I’m facing up to the fact. I mean it’s me that’s had that cancer, it’s me that it’s leaving for now, at least – and while it’s going well, it’s great, and make the most of it [laughs]. Will (75/CC), Interview 2

Being dead doesn’t frighten me... in the Western world you’ve got this devotion to the personality, to the, we are individuals...we’ve all had this intense feeling that “It’s me!” This is, this is important, this life. But after one’s grandchildren are dead there’s nothing really. It does sound nihilistic doesn’t it? I don’t know. [sigh] ...These are feelings, not facts. [pause] What the hell has this got to do with prostate cancer?...Well maybe I can cope with the mortality aspect of it because I’ve never been frightened of this particular disease...it’s a more or less concrete reminder of mortality. But I’ve always been conscious of mortality.

Stephen (84/PC), Interview 2

Janet was the only retired participant to express an uncomfortable change in perspective after her cancer treatment, when her plans to travel were overcome by her experience of illness:

I think I said even six months ago, absolutely totally altered you know my notion of the possible twenty years it might be, you know...I think that's remained much the same, er, that's its opened my eyes to sort of mortality...I used to assume as I said you know that I would be the one who would outlive my husband cos he's got his health problems, but now I'm not so sure. And that is a huge difference.

Janet (70/BC), Interview 2

The topic guides for the interviews did not deliberately address experiences of death and loss, but the majority of participants introduced the subject of bereavement when talking about family or showing photographs of family members. Participants talked about the deaths of spouses or ex-partners (1BC/2CC/2PC) and middle-aged children (1BC/1PC), the loss of their contemporaries in old age (2BC/2CC), the loss of a premature baby decades earlier (1CC), losing a father during their teenage years (1CC/1PC) and the impending death of a parent (2PC). For some, this emerged from the contemplation of their own mortality, for others loss provided a symbol of family strength and cohesion.

...the last couple of months [my mother's] been wanting to slip away. I think, sometimes, just the fight's too much. Um, she wanted to be, have her ashes in the woods where she grew up as a child...So we've taken down photographs and sold her that as a venue – told her there's a decent job to do to, to fertilise the snowdrop bed, and she's happy with that. Tony (69/PC), Interview 1

For three participants, previous family deaths from cancer led to expectations of loss among close family at the point of diagnosis. The association between cancer and death could bring back memories of family members lost in different circumstances, and lead other family members and friends to withdraw from interaction.

... [my children's uncle] died of pancreatic – no, not pancreatic – oesophageal cancer in January this year...So I thought, oh God, they're going to think I'm going ...if I mention the cancer word – that was another thing why I dern't tell em, for, if I mention cancer they're gonna think I'm gonna die. Laura (46/BC), Interview 1

Found a friend of mine on Monday night...laid in the front garden with his pushbike on top of him drunk out of his head, and I han't seem him for months...

he went "Oh I didn't want to come and see yer". This is what you get, you see...He said his dad...got bitten by a mosquito in Gambia and by the time they got to him his kidneys had collapsed and everything, so [friend] pulled the plug on him...He finished up with me all the time, wherever we went he was always there; brilliant time, absolutely, absolutely; and this is what we found in the garden on Monday.
Mark (62/CC), Interview

Other people's contemplation of participants' mortality became a concern at the point of disclosure, and could present a challenge to participants' ability to imagine recovery.

9.4.2 Resisting chronicity

Participants felt that their membership of the cancer "club" was temporary rather than permanent. The data evidenced contradictions in this perspective – in particular, between the need to construct the cancer episode as acute and participants' acknowledgement of the possibility of recurrence. Ruminating on recovery, descriptions of their illness as acute rather than chronic were invoked as a way of moving beyond the curve in life's pathway brought about by cancer:

I think at the end of the day, if the radiotherapy works then, then that's the end of it. Jack (65/PC), Interview 1

[The oncologist] said "Eighty-five percent success" [with internal radiotherapy], which is pretty good. So we went for that...at my age I've been a complete success...I mean my father was a bookie and he can't get eighty-five percent. [laughter] Derek (81/CC), Interview 1

...that's how I look at it, it's been and gone, you know, I've got over that, and then whatever's thrown at us now is not as important, it's just little things. You know, we deal with it and you move on. Gill (40/BC), Interview 2

It's been, it's done, it's gone. Laura (46/BC), Interview 1

It just feels I've had an illness and it's been cured. Tony (69/PC), Interview 2

How am I?...as far as the as the cancers concerned it's really very much something that's way in the past...I talk about it now as the tumour...I've become

more aware of choosing that word rather than cancer. I think it's because, erm, it's self-contained. Tumour refers to that part which has been removed – not, eugh, all over. Eleanor (71/BC), Interview 2

This view of their illness as acute is not always supported by other people in their family or social circle:

...[husband]'s always very used to the notion of, that he has cancer, and he'll often ...talk to people now and say "Janet's got breast cancer", whereas I'm always saying to him "Well I'm not sure I've got it at the moment, cos I've had the treatment, and I may well get it again but I'm not sure I've got it at the moment". Janet (70/BC), Interview 1

I've got a couple of friends, one of them rings a lot, and she did tend to be a little bit more intense and say "You've been through a lot, Ellie", an' all this...I'm like, "Yeah, it's gone, just...[whispers] shut up!" [laughs] Ellie (64/CC), Interview 2

Even now [father-in-law] says to me, "You're not well". I said "I am well, I'm fine."...we didn't make it an issue...they said fifty per cent of it is in your mind, how you deal with it...if you let it overtake yuh, it will. Gill (40/BC), Interview 1

Expressions of resistance to the concept of cancer as a chronic condition are accompanied by an acknowledgement that cancer cells might remain in the body, undetected. Despite this acknowledgement, the coining of the term "remission" by other people, with its connotations of dormancy rather than cure, is unwelcome – it does not fit in with the idea of an acute illness. Fear of recurrence can be intensified by outpatient clinic visits:

It's quite hard when you're going to oncology and you're... the people you see, you see a lot of people with secondaries...I think it made me more aware of the possibilities of the return of the cancer...it's quite difficult to explain where you are...people either say "Have you got the all clear?"...or they'll go "Are you in remission?"...I don't have the proper words to explain how things are...I don't know what they call this period of time until they do give you the all clear...what is it? Maybe I should ask. Clare (55/BC), Interview 2

The trouble is, when you say you're in remission, people think, oh you're OK, that's it...you're back to normal. You aren't...I've got... maybe got rid of it for now, I always think in the back of me mind that I could come back...It in't negative to me. it's life, it's fact. You've got to face up to the fact that it could come back. I mean honestly. Will (75/CC), Interview 2

People do ask how I am yes. Now I can tell them I've done a year, and you know, been OK for that, and people say "Now you're in remission"...I don't think it's fashionable. Somebody told me very strictly I have to use it on official documents and travel insurance – "in remission"...a bit like I don't like the word "survivor". "In remission" suggests...it's all going to come back with a vengeance, so I'm not very keen on "remission" – implies an interval, like an intermission. Janet (70/BC), Interview 2

Where fear of recurrence is expressed, this does not rule out the possibility of feeling "mended" (Clare, 55/BC, interview 2). The breast cancer participants expressed this most keenly – maintaining the belief that the disease could have been an acute episode alongside the fear of recurrence:

I'm not going to lie, I think about it once a day...it's not gonna not be there, I don't think. But life takes over doesn't it?... still got to earn some money, still got to get the kids where they want to be. Life just does, dunnit? Yeah, I think I'm not in the grip of it any more, thank God. Laura (46/BC), Interview 2

*...how do I know that that cancer isn't going to come back somewhere else?
...there's no way of telling, you know, I've just got to get that out of my mind and get on with my life...I try to switch off and think holidays and what I've got to do and, you know, just planning, well plan your life away really. [laughs] Harriet (72/BC), Interview 1*

It's always in the back of your mind obviously...I think now, well now, I've had cancer and I know that I could have, it might not have worked, mightn't it?...the treatment and one thing and another. It could have got worse instead of getting better and curing it. Liz (48/BC), Interview 2

The counterpoint to this is expressed by Janet (70/BC), who describes cancer as an entry point into a chronic state that will continue until five years beyond treatment:

I remember when I, when we finished our last interview...I said I would hope that the experience would be less raw [at second interview]...even at the time I didn't like that really because I felt er, even at the time I felt "raw" wasn't quite the right word...it's totally wrong...the point is I now know that I've got this four years ahead of me and there's no way its less raw – it's the same, if not worse, somehow. Janet (70/BC), Interview 2

9.4.3 Marking the timeline

Twenty three participants spontaneously talked about special events in their lives, such as celebrations (weddings, Christmas, birthdays), holidays and family parties. This was not deliberately addressed by the interview topic guides. Threads of the data in first and second interviews demonstrated how special events could act as imaginary markers of recovery and (for some) survival along a timeline stretching into the future, helping participants and their families to envisage specific goals. In the first interviews, descriptions of special events emerged from the photographs participants had chosen to take, and from talk about the urgency of treatment, delaying disclosure, displacement activities and networks of social support. Oncologists sometimes positioned holidays and birthdays as more important than treatment schedules. Will's surgery was delayed for a week to allow him to go to New York to celebrate his wife's birthday; Laura reported a feeling of inequity when another patient's radiotherapy was brought forward to enable her to finish in time for a pre-booked holiday (for Laura, the gap between surgery and radiotherapy provoked anxiety).

Special events brought participants into casual contact with people who they did not see regularly; disclosure could become more difficult at these times as cancer was seen as a poor fit with "having a good time" (Eleanor, 71/BC) – for the participant as well as for their social network. Ignoring their diagnosis, and escaping conversations based around it, could be helpful for participants in maximising their enjoyment. The activities surrounding special events were a distraction – tasks were time-limited, with

a positive focus, and participants described their involvement in ways that did not suggest experiences of stress or anxiety:

... it was coming up to Christmas [just as chemo started]...what we do [at work] is we support a particular group of women – so I went and did all the Christmas shopping, that sort of thing, did all the present wrapping. Same for my own church...they do a soup kitchen – an' I wrapped up parcels for that...it's like Father Christmas's workshop, the dining room. [laughter]...that was helpful to have sort of positive things, and to think that I could take a little bit of a load off people who I knew were really busy. Clare (55/BC), Interview 1

...with carers this is often said, when you go out for the day you don't really want anything that's about caring or about breast cancer, you just want distractions and, about knit your own Christmas decorations and that sort of thing...the most important thing, I think the main benefit is meeting other patients and survivors...the main thing is the solidarity...I would sort of stomach the “making a festive candle” for the benefits of meeting people. Janet (70/BC), Interview 1

...soon after I was diagnosed [my daughter's] partner...asked her to marry him... she said she wanted a winter wedding, so he said “Well I'm not waiting till next”. So they're getting married in December basically [laughs], so in six months they've had to organise this, this wedding. So that, that's been a distraction...I've got a garage full of wine...So I've got to get – is it thirty-six, seventy-two bottles of wine? – to [town] early on in that week. Jack (65/PC), Interview 1

For participants with large extended families, social gatherings marking special events were a catalyst for bringing people together into the same physical space. The presence of family brought a sense of belonging, a reinforcement of identity, and the reaffirmation of relationships:

The next big [family] event will be in June...cos there's a lotta birthdays. But we're gonna like have it at one particular day...we're having it at [local venue], at a big club there...and then everybody will be there. They always get together. All the nieces and nephews try and get together... there's four missing [on the photo] cos

two live away...they couldn't come. But in June everybody'll know in advance and everybody'll just turn up. Fiona (69/CC), Interview 1

Have you been here since it was my birthday? I can't remember when it was when you came...Well it was beginning of August, me birthday...I had me surprise party, and they came, and they came all the way from Essex and I didn't know. [Son] arranged it all...we went walking in house and I opened the door, me cousin, me cousins from Doncaster and their husbands was there and our friends from... on [their road]...And then blow me, about an hour later, who come rolling up, but [close friends]. Couldn't believe it, I couldn't stop crying all day. I was crying all day. Derek (81/CC), Interview 2

It's a photo of [wife]...she's a, has lots of demands from life, but she, she just sort of put aside the time to make it feel dead easy for me to get lifted in and out of treatment...it was really nice yesterday, on her birthday, to sort of start with breakfast in bed and a rose and go for a walk up on the Dales and take her out for tea and end up in the [pub] for a fish and chip supper at Whitby and come back completely knackered [laughter]...all the worry about...everything else that's going on, we just went, "Phht, this is your day". Tony (69/PC), Interview 1

The symbolism associated with celebratory events could act as a permanent reminder of a sense of belonging – as placeholders for romantic and family identities. Liz (48/BC) presented a photograph of a vase of lilies, bought by her husband – a flower that was used for her wedding bouquet. Her husband had brought lilies home throughout her treatment. Derek (81/CC) presented a photograph of his hand holding his wife's hand, with the wedding ring showing – they had been married for sixty years.

The shared nature of celebratory events allowed them to be used as markers of progress by both participants and their families, and for people in other social worlds where participants had a firm footing. Clare photographed a celebration at work:

We actually had a staff day, but they also, part of it was to celebrate my recovery, so that's actually buck's fizz it's not just orange juice! [laughs]
Clare (55/BC), Interview 1



Figure 28 *Derek and his wife holding hands. “It means how much I love her, dunnit? It’s good” (interview 1).*

The motivating force of celebration seemed to be instinctively recognised by many participants’ families during their illness. Derek (81/CC) showed a photograph of cards celebrating the arrival of a grandson, and explained the significance of a birth in the family in relation to his illness – his wife had kept the impending birth prominent as a way of “egging” Derek on. Layla described the importance of maintaining continuity for her daughter with a birthday celebration in hospital after her surgery. Maura’s holiday to France to visit her brother’s war-time grave was her reward for finishing treatment.

Arthur (77/PC) referred to celebratory events as “milestones” for survival, and Liz (48/BC) described how these markers can have negative as well as positive significance, but still provide orientation towards the future:

Is it going to work? I knew I was gonna have some treatment but I didn’t know definitely it was gonna start until after Christmas. So of course – am I gonna be here next Christmas?...So aye yeah, so it’s a milestone that I got Christmas. I’m looking forward to next year... If somebody says “I been for a wee and I’ve passed a bit of blood”, get to the bloody doctor’s. You’ve got to be...vicious with them...if they don’t go then they’re not going to see next Christmas...cos you’re going to the crematorium and not coming home. Arthur (77/PC), Interview 2

With losing [husband]'s granddad as well just after Christmas, and then I had the breast cancer, and yeah, it's just been one thing after another, and it's like you just want it gone, don't you, and start a fresh year. Liz (48/BC), Interview 1

Three participants did not mention celebrations in their interviews – Pete (75/PC), Mark (61/CC) and George (82/CC) took part only in first interviews, had disclosed their cancer least, and had the smallest networks of social support. Pete and Mark each mentioned a single commemorative event, Pete describing his visit to his son's memorial tree, and Mark talking about a funeral, in connection with the shrinking of his family network:

I've got, no – me sister [lives away]...I've got another one who lives a bit further up...and me brother lives up the other side of [the city]. I don't get on with any of 'em. Well I do get on with me sisters...but I don't get on with me brother, we had a big fallout, ex-wife thing and all this, we had a big fallout, so. Apart from me nan's funeral, I aren't seen any of them since then really, so...they don't know anything about it [the cancer]. Mark (62/CC), Interview 1

For Pete (a widower living alone) and Mark (who did not disclose his illness to his wife until many weeks beyond treatment), keeping diagnosis private was a choice – for George, who lived alone in a flat in sheltered housing and suffered from memory problems, it was not. Celebratory events as an expression of support and as a way of orienting thoughts towards the future relied on the support of multiple other individuals in participants' social worlds.

9.4.4 Making decisions about healthy behaviour

Participants' accounts described three main influences on undertaking healthy behaviours after treatment: health behaviours before cancer diagnosis, pre-existing illness before diagnosis and perceptions about ageing. Their confidence to undertake healthy behaviour, and their conception of what "recovery" meant, was also mediated by their social context and cancer type, which is explored where relevant.

Participants did not connect their decision-making about healthy behaviour exclusively with their cancer. The majority of participants described pre-existing behaviours

that they felt stood them in good stead for recovery: cancer treatment had interrupted these behaviours. Clare (55/BC) characterised this as a break from the norm – she had “visited” healthy behaviours during treatment, and resumed them afterwards:

Still managing to do a little bit more baking and a bit of painting... We're back walking and stuff. They were things that I'd visited [when poorly] and come back to. Clare (55/BC), Interview 2

This interruption was felt keenly by breast cancer participants who had experienced chemotherapy or radiotherapy, and by Mark (62/CC) and Ellie (64/CC) and Will (75/CC) as a result of digestive disturbances after colorectal cancer treatment. The concept of culpability for illness (see section 8.3.1.2) played a role in motivating dietary change. Ellie (64/CC) and Liz (48/BC) and Janet (70/BC) discussed the idea that body weight or diet can contribute to a susceptibility to cancer, and this motivated them to exercise and adopt healthier eating habits. Fiona (69/CC) changed her attitude towards her (and her husband's) diet:

*I have changed... I used to bake a lot... I have stopped doing that now and stopped for both our health sakes really... not that I think that that did anything to me bowels before, it's just that you start and think, don't you?
Fiona (69/CC), Interview 2*

The physical sequelae of treatment encouraged inactivity or changes in eating patterns that led to frustration – the bigger the change from pre-diagnosis experience, the higher the level of frustration. Frustration could directly motivate the resumption of activities, but was low among those who had a lower level of physical activity before diagnosis, and in these cases treatment effects could have the opposite effect and dampen motivation. This was particularly the case where other life issues such as family responsibilities took priority. Lesley (43/BC) and Eleanor (71/BC) described contrasting approaches towards resuming exercise, given the need to minimise infection during chemotherapy:

I went to the gym – I wasn't allowed to do any cardio through me chemo, but I went to pilates, yoga.... Do people actually use the gym when they've got cancer?

I don't know...I was really fit at my diagnosis, and I thought, no, I'll keep this up, throughout my chemotherapy. Lesley (43/BC), Interview 1

My exercise...since I gave up full time work has been swimming...I was advised not to swim [during treatment], because obviously you can pick up bacteria in public baths...my good intentions are still good intentions... [husband] and I were talking about it just the other day, saying I must get back swimming.

Eleanor (71/BC), Interview 1

Eleanor was awaiting the arrival of a new grandchild, and undertook new family responsibilities in the year beyond her cancer treatment. Lesley, who had grown up children but no grandchildren, was highly motivated to resume exercise – she was able to take time away from the family to join a local running club.



Figure 29 *Lesley's running shoes.*

For retired participants Mary (70/BC), Maura (81/BC), Janet (70/BC), Derek (81/CC), Greg (78/PC) and David (80/CC), pre-existing illnesses had limited the ability or motivation to exercise or eat well before their cancer diagnosis:

I eat what I want to eat. Well I have to eat what I want to eat, [otherwise] I vomit it all up [because of reflux], you see. And what saddens me is, I used to love to go out with my daughter for meals, but it's just a waste of money. Cos I go and have what I think I'll eat, and then...I come home an' I vomit it all up.

Maura (81/BC), Interview 1

...I miss walking with me mates, cos I can't do it, through this stroke...when you go out here, for about a mile, there's a drain...we used to walk two stretches of that...twice a day...This is me exercise bike [mobility walker] [laughs]...I walk this bloody thing up and down this Grove twice/three times a day...when the weather's right...[Interviewer: So what's the motivation to exercise?] Well I wanna get right. [laughs] I, I'm, I'm, I'm a cripple in me own home.

Derek (81/CC), Interview 1

I've had no effects [from the cancer]. I mean me back's getting worse and me arthritis is getting worse, but I'm getting older so it's not getting any better...the more pain you're in the less you can move around so. It's something you can't get yourself out of unless you can get yourself up. And when you're in pain you daren't go anywhere because if you get halfway there you might [laughs] not, not be able to get back, so. Mary (70/BC), Interview 2

For other retired participants, the experience of another acute health incident – for example, an aneurysm (David, 80/CC), a stroke (Derek, 81/CC), hospitalisation after a sudden collapse (Mary, 70/BC), a gallstone in the pancreas (Arthur, 77/PC), and neurological absence attacks (Greg, 78/PC) – had provoked them to give up poor health behaviours in a more immediate way than cancer:

I gave up smoking before, long before, long before that [cancer diagnosis], yeah, yeah. I had I got on these patches...it's unbelievable to me somebody to be in [hospital] for cancer and sneaking outside to smoke! David (80/CC), Interview 1

I stopped [smoking] immediately [after his stroke]...I didn't wanna stop smoking, but I'm bloody glad I have, cos I don't ruddy cough in a morning and I don't use me inhalers...I just didn't wanna smoke...Everybody I've told is astounded.

Derek (81/CC), Interview 1

I went out with me brother and...I had half a shandy, I had about three sups of it and I collapsed and they rung an ambulance...I said that I'd had like three sips of beer, they called it "alcohol related" and sent me home. So I came home and I said "I'm never gonna have a drink again". Mary (70/BC), Interview 1

...of course I stopped drinking...we used to drink half a bottle each every day until I started with these tablets [for absence attacks], and they affect your kidneys apparently...they advised me not to drink regular but you can have an odd glass now and then. Greg (78/PC), Interview 1

Like Greg, Derek (81/CC) and Jack (65/PC) represented reduced alcohol consumption as not drinking. The subject of alcohol was not addressed in the interview guide, but introduced by participants. In his second interview, Jack stated that he had stopped drinking during radiotherapy, but resumed moderate drinking after treatment, despite uncomfortable symptoms:

Well I stopped drinking altogether. During the radiotherapy...we went out one night out of seven weeks for a drink... But apart from that I didn't have a drink... alcohol and coffee actually made the symptoms worse...to be fair it's only a, a slight discomfort for a short while and it's not a problem...I do like the odd drink. Jack (65/PC), Interview 2

Derek introduced a discussion of alcohol with a photograph of a pint of beer: "I don't drink! [Interviewer: That's a Guinness!]" (interview 1) – he put his increase in appetite after cancer treatment down to Guinness, "and me whisky". The same discussion arose in his second interview:

Derek: I don't have my wine now. [laughs]

Wife: No, but he does have his Guinness every night, or a beer, don't you? And a whiskey before he goes to bed.

Derek: Oh, I'd die without that. I'd die without that. [laughs]

Retired participants perceived ageing as a process that might compromise their ability to undertake healthy behaviours, claiming that the body was wearing out. Informal talk about health difficulties had become more frequent as they had aged.

I become short of breath now, which I never did. I used to do a hell of a lot of walking. I still walk about at least a mile in the morning with the dog...when I'm short of breath...I get a pain in my back just up here but it affects me walking, me legs...I've realised me potential and me limits now...everything's wearing out.

David (80/CC), Interview 1

...when you get to our age you discuss it with all your friends, of all the illnesses – that’s the topic (laughs)... [Interviewer: When did that start?] Sixties I think.

Greg (78/PC), Interview 1

When my family met up last time and [brother] had been through prostate [cancer] and so on, and somebody else had been through another problem, and I just said, “Right, we’ll have one conversation about health, it’ll last half an hour, and then were not going to talk about that anymore, so let’s get it all out”. So, “How are your bowels?” “How’s your heart?” “How’s this?” ...OK. Now then, “What are we having for supper?” Tony (69/PC), Interview 2

Despite this, age could be a greater motivator for healthy behaviour than cancer – although the means of achieving it (for example, gym membership) was dependent on levels of affluence and social support.

We go to the gym three times a week...I’ve been going ten years now ...it’s a social event...we do gardening, we swim... when you get to my age, if you stop moving then everything stops moving, so even if it hurts a bit you still got to keep moving it! [laughs] Greg (78/PC), Interview 1

I think I might go out for a little walk tomorrow. Cos what was...I was reading somewhere about, um, it helps you, old people, to stave off dementia if you just have twenty minutes’ walk a day. Well I must say that, you know, sometimes I’m very forgetful, I think “Ooh, is it creeping up on me?” Maura (81/BC), Interview 1

Fifteen participants across all three cancer types talked with a level of confidence about their motivation to resume the activities they enjoyed prior to their diagnosis, including the majority of breast cancer participants and prostate cancer participants. Confidence in recovering previous levels of activity within the year after treatment was lowest among the colorectal cancer participants, whose digestion was still disrupted six months beyond treatment, and four of whom (Derek, 81; Will, 75; James, 75; George, 82) were struggling with other health problems (for an exploration of the role of comorbidities, see section 8.3.3). This confidence could be encouraged or inhibited by family members and health care professionals – Ellie had been encouraged by her daughter’s health behaviours:

Me daughter's been so good though, and she's shaming me...she's losing loads of weight and she's doing loads of spinning and gym and...I'm thinking ooh...she's trying to reduce portions as well. She said "We eat too big portions", and I think, hmm. I'm taking it on board [laughs]. Ellie (64/CC), Interview 2

Health care professionals' advice was interpreted in a very literal sense, sometimes from a single communication that resonated, affecting the level or nature of activity perceived as appropriate by both patients and their families. Without ongoing advice or information about change over time, the appropriate resumption of activities could be compromised, or policed by family members in a way that reduced participants' confidence in their abilities.

I thought "Oh gosh, I need to get rid of some of this fat, weight, if he's cutting through I need to reduce this big stomach"...quick, go to the gym...then when I went to the hospital they said "Don't try and lose weight, you need to build yerself up"... when I came out of hospital after the six weeks...I'd put on weight...I was really peeved after they'd promised I would lose some weight! [laughter]

Ellie (64/CC), Interview 1

What got me is, when I come out of the hospital and stuff, they wouldn't let me do owt. An' I thought, I felt lazy. I thought, I can't do owt. They won't let me do this, they won't let me do that – what, what the hell good am I? I can't do nothing. Will (75/CC), Interview 2

Two participants in particular displayed a high level of confidence in decision-making about healthy behaviours, Lesley (43/BC) and Maura (81/BC), both of whom had worked in health care.

I'm debating whether to take meself off statins. Because I am sure that my joints have not been right since I was on statins. I mean I read an article about a man in the paper the other day stopped taking them, an' he said all his knee pains have gone... [Interviewer: So who do you discuss all those medical things with?]

Nobody! I do me own diagnosis, me own treatment! Maura (81/BC), Interview 1

All participants talked about eating and drinking healthily and exercising when asked about regaining health, but beyond these behaviours, the process of recovery could be

defined in more than one way. One choice for participants was to adapt to lower physical capabilities, temporarily (Gill, 40/BC) or permanently (Janet, 70/BC). Recovery could be further conceptualised as progressing back towards pre-diagnosis capabilities. All of these processes could be construed as “work”:

I don't think I'll suddenly leap to life eighty, seventy-five, as I say! No I'm afraid that...I tend to be pessimistic. I've got to work with this loss of energy, I've got you know, and er, I've just got to work with it and do as best as I can and think of strategies. Janet (70/BC), Interview 2

...there's a physical thing, which is heading back, and I expect that to take a while, but some of those photos were saying I'm battling on with it [laughs]... whether I'm actually right in the degree of activity and hard work and so on that you put in aids the help, getting better process? I think it does.

Tony (69/PC), Interview 1

Janet and Tony were of a similar age and level of education (Janet had experienced chemotherapy, Tony radiotherapy), but shared little in the way of social context. Janet lived in a small terraced house in an urban area, and undertook a great deal of physical work looking after her husband who had suffered prostate cancer and a stroke. Tony lived in a detached house in a rural village – at the time of his illness, his extended family responsibilities were considerable – but his wife was physically fit and active and he described her as an invaluable source of support.

9.4.5 Looking for closure

Participants reported a range of physical effects from treatment that persisted into the following year, from fatigue, pain after surgery, skin complaints and lymphoedema (from breast cancer treatment) to sexual difficulties (breast cancer, prostate cancer) and digestive disturbances (prostate cancer, colorectal cancer). By the time of their second interviews, follow-on clinical care had addressed physical issues either directly by providing further checks, by scheduling further surgery, or through giving advice about coping with symptoms, including reassurance that some symptoms were likely to resolve on their own over time. This theme investigates how, in the year beyond

treatment, participants expressed feelings of a lack of closure after treatment, and frustration as they attempted to understand what was required of them in terms of managing their own follow-up. It also considers talk about group interventions for cancer patients, which arose in six of the interviews (4BC/1CC/1PC).

The end of treatment was perceived as the point at which surgery and/or chemotherapy or radiotherapy had been completed. Fifteen of the seventeen breast and prostate cancer participants knew that they would have long term hormone therapy in the months after their initial treatment, and prostate cancer participants continued to engage in blood tests to check for potential problems. The transition from intensive short term treatment to hormone therapy via injections (prostate cancer only) or oral medication was unclear to participants, who had a sense of having a foot in two camps – with their specialist (secondary care) and their GP practice (primary care). An uncertainty about protocols was evident in their accounts:

At my last session at the clinic, which would be with the oncologist, I think it was – or was it the chief radiographer, radiotherapist I mean? I can't remember, but whoever it was I saw said that there would be an annual check-up, but nobody said when the annual bit started. So I didn't know whether that meant from the operation, or from the beginning or the end of the radiotherapy, I wasn't really very sure...I was umm-ing and ah-ing about whether to give somebody a ring.

Eleanor (71/BC), Interview 2

The first one [blood test] I had done in January after the radiotherapy... because they told me I would be seeing the registrar and my appointment was due in January I went, did it on my own basically. Just went to the doctors and said can I have a blood test...the actual appointment didn't come through til about the April...a long time after the event...So then I thought he said he would see me again in another three months. Well nothing happened, so I made this appointment with the nurse...I'm still waiting to see the registrar again although the three months is probably up now, but they never come through on time.

Jack (65/PC), Interview 2

I phoned up [about consultant appointment] and said I was expecting one at six months, and the PA said, "Oh, we're running a bit late...we'll do something about it". And then another month and absolutely no correspondence...and you've got to get, have a blood test a week to ten days before to get results through anyway. So I phoned up and said "How's it going?...You still haven't sent me anything."...I had a letter virtually the next day...so I think you sort of feel that you're triggering stuff...I don't know whether it matters whether you're exactly on six months or not. I hope it doesn't! [laughing] It might!

Tony (69/PC), Interview 1

Clare summarised the frustrations as a lack of joined-up care:

Just after Christmas I got an appointment through for a [routine] mammogram... then I got another one... "Erm, do I really need to come to this?"...and they're like, "Yeah, just ignore it, we'll take it off". [laughs]... I went on holiday and I just, like trying to get it sorted out so they didn't have me going for a heart scan while I was on holiday, and my Herceptin dates were all put in, and was like, "This is when I'm going on holiday", and I spoke to so many people, and what happened? The week before I went on holiday I got an appointment to go for a heart scan in the middle of the holiday!...and everything was sort of tied around it...I don't think there's much joining up, no, no. And you expect it. Well, I do – I expect everything to be joined up...everybody's got access to everything and it'll all work – but no. Clare (55/BC), Interview 2

Contact with specialist nurses as a source of help after treatment did not arise in the interview data – most participants were offered support but either did not request it, or felt that it did not materialise in the way that they had expected. Derek (81/CC) received a phone call from a specialist nurse on finishing treatment, but on reporting that he was managing, the nurse postponed her first visit; a second visit had been promised but not followed up. Participants referred to specialist nurses as reluctant to communicate, or exempted themselves from the need for specialist nursing support:

I wasn't offered to see a Macmillan nurse, but there's a lady who lives in the village who works with Macmillan...she put me onto a Macmillan nurse who, she came to see me, and more so to give me the grant that we're entitled to. But she

was a Macmillan nurse who goes to someone who's at the end of their life...I only saw her once. She was gonna come and see me again after I'd got me results, but I never saw her again...I didn't contact her...no-one ever rang me or anything... I don't think I would have wanted to open up then, again because I was, I wanted to be in the mindset where I was gonna be OK. Layla (44/CC), Interview 1

I thought I could get by without [Macmillan nurse support], to be honest. I thought they'd probably got enough on without somebody like me [quiet laugh], who's at least recovering. Will (75/CC), Interview 1

If I'd got depressed or something like that...they would maybe have got a Macmillan nurse to come and see me. Arthur (77/PC), Interview 1

I think, psychologically, if there was something there where I felt – you know – it'd be either the GP, or one of the Macmillan nurses, probably. [Interviewer: Do you have a Macmillan nurse?] I've never contacted her, no. I've had a number, I've had a name, um, but I've never contacted her all the way through, so. I think I've...sort of coped with it myself, and the family, my own way, sort of thing. Lesley (43/BC), Interview 2

Participants were asked whether they consulted with their GP after their cancer treatment. Thirteen participants reported arranging GP appointments (7BC/6PC/3CC) – Lesley (43/BC) found the visit helpful for follow-up in a way that specialist care had not been. For most, the consultation had been about ongoing medication or worrying symptoms. Four reported retirement of their regular GP, or GP changes in their local practice, and frustrations in accessing appointments or resolving symptoms. Fiona (69/CC), Liz (48/BC) and Janet (70/BC) placed greater trust in specialist opinions, and saw primary care as lacking in expertise:

...they don't really know what you're going for, they don't really know you, and I just felt like they didn't wanna know, to be honest with you – just like, "Oh yeah, here's your tablets, go on" [dismissive]...I got more help from the hospital. Liz (48/BC), Interview 2

Retired participants Eleanor (71/BC), Stephen (84/PC) and Janet (70/BC) remarked on the difference between their present experience of primary care and the continuity of

care they had felt with GPs earlier in their lives – “We were people rather than ten minutes of symptoms” (Stephen, interview 1). Maura (81/BC) distrusted GP advice: “You get different opinions every time you go” (interview 1). They expressed the feeling that the primary care system had become impersonal and difficult to access:

Now the surgery is such that...I don't think I have a named doctor, you just see whoever's there and they spend more time looking at the notes on the computer really...because they don't know you. Janet (70/BC), Interview 1

I think this is a national problem...it's taken five weeks to get an appointment just to review me tablets with a nurse, and I just can't believe this.

Arthur (77/PC), Interview 1

Formally organised group support sessions in the year after treatment were generally not well received by participants in this study. Of the six participants who talked about formal group support, four felt that they were not “the type” to benefit from group sessions, or that their cancer situation had not been extreme enough to warrant sharing in this way. To Eleanor, group sessions were for people who had “grittied their teeth” through chemotherapy and had to “fight” to keep going:

I feel that I haven't needed to do any of that, because I've been lucky enough for it to, for it to have been caught when it was relatively minor.

Eleanor (71/BC), Interview 1

I've always kept meself to meself, always have done. So yeah, so haven't joined any groups or anything, or anything like that [laughs], I'm not that type of person. Layla (44/CC), Interview 1

...some people just like sitting discussing it, I don't. Nothing I can about it at end of the day, if it went the other way it went the other way and that was that, mmm. I'm not that type of person really. Mark (62/CC), Interview 1

I didn't want to sit round talking about my treatment! [laughs]...I didn't want to get into all that...you move on, get on with your life, then forget about it – and then something comes to remind you, dun't it? Lesley (43/BC), Interview 1

Only Arthur found a support group that felt comfortable – a local, informal group. He contrasted its informal, gentle approach to an exercise session with his perceptions of the approach of the charity Macmillan Cancer Support:

I found out about a local [prostate cancer support] group and I just went and got involved...We did have a lady come..about doing exercise...I got to be careful here, because Macmillan's, they they do one and they do a video...If I was going in for the London marathon, that's maybe what I want to be looking at. But it's, to me it's too severe. Now this lady...it was just more or less chair exercises using a flexible nylon like scarf, it just did this sort of thing [stretches arms up]. Which seemed like a good idea. Arthur (77/PC), Interview 2

The participants in this study felt that they had optimistic prognoses in comparison to other patients, and that the aim of specialist nursing and cancer charities was to support people who were suffering with more severe experiences of cancer.

9.5 Chapter summary

The final chapter of findings has explored how participants made adjustments within their social worlds to recalibrate and move forwards after cancer treatment. Many participants had to come to terms with some level of change within relationships, despite a resistance to the idea that cancer had fundamentally changed their identity. For most participants, other changes in health status, living environments or family networks were as significant, or more significant, than their cancer. Attitudes towards work shifted where participants felt their skills had been diminished during sickness absence, and it became less central; it did, however, remain a key focus for those who returned to their job. Throughout the cancer experience, participants harnessed everyday domestic resources and the local environment in ways that helped them to regain the control, comfort and continuity that cancer had disrupted. As they continued to make meanings from the experience, they resisted the idea of cancer as a chronic condition and held on to the future by making plans. In the months following the end of treatment, they discovered the need to be proactive about their ongoing care, and made their own decisions about how to manage their future health based on the context of their individual experience.

Chapter 10: Discussion

...quite clearly cancers in general are nasty things to have...But the other thing, of course, is that nobody carries a placard round saying "I've been cured".

Stephen (84/PC), Interview 2

10.1 Introduction

This chapter begins by exploring the limitations of this research project, and the ways in which these are reflected in the analysis. It then brings together the conclusions of the findings sections to offer answers to the study's research questions, discussing where the findings reflect previous research and where they raise novel issues. Issues related to theories of existentialism, identity and biography used in the existing literature are signposted where relevant. The research questions for the study asked:

- What are people's key concerns when they complete treatment for a primary cancer with curative intent?
- How might meaning-making shape people's experiences in the year beyond treatment?
- How do people make use of everyday resources to adapt to life in the year beyond treatment?
- How might demographic characteristics mediate experiences of adaptation and recovery?

Discussion of these questions is followed by a summary of the key issues, before an examination of the implications for practice and research in Chapter 11.

10.2 Reflections on the research: limitations and strengths

Chapter 4 discussed in detail the limitations imposed by the photo elicitation method (section 4.5.2.1) and data collection procedures, which affected the longitudinal aspect of the study (see section 5.4.2). First interview data was collected at an average of five

months beyond treatment, and second interview data at an average of thirteen months beyond treatment. The difficulty of sourcing participants at specific timepoints, and the inclusion of data from all timepoints within a single coding framework, reflects similar issues in the existing literature^(82, 136, 140, 160, 161, 181). The findings of this PhD study examine adjustment to cancer in the year beyond treatment, but do not assume that the process of adjustment is limited to this time: the findings explore how the experience might be negotiated, rather than completed. The labelling of a cancer diagnosis as a transition from health to illness must also not be assumed, given that six participants reported comorbidities. The following reflections discuss the nature of the study sample and the ways in which this might have influenced the analysis, providing some caveats to the interpretation of the findings.

The study relied on a self-selecting sample. Recruitment did not control for issues such as social status and age – the only purposive criterion was the recruitment of ten participants from each of three cancer types (breast, prostate, colorectal). The study originally hoped to recruit thirty participants, but recruitment was slow and had to be closed after twelve months with twenty-six participants and a total of forty-three interviews. Deliberately controlling for age and gender would have been possible over a longer period of time via oncology clinic recruitment; a different approach via community channels (such as outreach organisations) in specific areas of affluence or deprivation would have offered a level of control over criteria connected with social and economic status. This was implied using postcodes alongside the participants' descriptions of their circumstances, and was not a central focus in the findings.

The study was open to all ethnicities, but the sample was culturally homogeneous – all participants were white British, and their experiences cannot be generalised to other cultures. A clinical nurse specialist who assisted with recruitment asked whether a Sikh gentleman could be accepted on to the study, but reported feeling uncomfortable about sharing study details with him, stating cultural differences and potentially differing illness practices as a reason for not including him. The literature review suggests that cultural differences affect adaptation to cancer (section 2.3.3). Purposive sampling from specific ethnicities, a method reflected in existing literature from

Asia^(151, 160, 163) and North America^(145, 147), allows for deeper data saturation than studies including a minority of participants with different ethnicities.

Recruitment took place at a single hospital location: the clinic “culture” described in section 8.2.2 may not be representative of how such clinics operate in other locations. The positive characterisation of the radiotherapy unit (section 8.2.2.1) does demonstrate the possibilities that some clinics may have open to them to help patients benefit from the time-limited social world of treatment waiting rooms. Participants in this study were aware that they lived in an area with higher cancer rates than the national average, and saw the excellence of their care as a response to this. Their ability to adapt will have been influenced by the good standard of care at the hospital where recruitment occurred. This reinforced the intention to focus on the assets developed by this group of patients, in the hope that this might suggest ways of thinking that might help other patients in a similar situation.

The strength of this study lay in its research methods. Photo elicitation kept issues significant to the participants at the heart of the study, and directed their attention to the social and material resources available to them in their home and their local area. Interviews using participant-generated photographs provided threads of data which could also be pursued with the minority of participants who did not wish to take photographs. The study was not able to fully exploit situational analysis techniques, given its single source of data, but these techniques proved crucial in balancing the role of individual subjectivities against the role of other people in participants’ meaning-making. A broader situational analysis study taking all stakeholders into account might further elucidate the characteristics of the changing arena of survivorship (this is discussed further in section 11.4).

One further note must be made about the issue of embodiment, which is inseparable from the subjective experience of cancer but was not a focus of the study. Williams⁽¹¹⁸⁾, writing about the sociology of chronic illness, acknowledges the possibility of “writing the body out of existence”^(p56), referring to an increasing emphasis on the relativism of the concept of “normality” which allows it to encompass a wide range of different states – a concept pertinent to cancer and its concept of the “new normal” (see section 1.3.2.1). The focus of this thesis is the use of resources to

adapt after treatment: it intentionally drew away from an emphasis in previous literature on embodied experience. Participants were not asked to avoid talking about physical symptoms or photographing the body, but their expectations that the symptoms of treatment were minimal and would pass contributed to decentralising embodiment in their images and interview talk.

10.3 What are people’s key concerns when they complete treatment for a primary cancer with curative intent?

At the end of treatment, participants had become sensitised to the generalisation of cancer patient experience in communications with professionals and lay people, and became conscious of the expectations that this established around their behaviour. They responded in two ways: by searching for ways of reinforcing their pre-cancer identity, and by learning to manage disclosure. This section considers these issues by exploring what made care feel personalised, and how participants shaped the potential audience witnessing their cancer. It also considers participants’ frustrations with the transition between secondary and primary care.

10.3.1 The personalisation of care

In chronic health conditions, the psychological distress and treatment effects that accompany the onset of illness disrupts people’s sense of identity^(180, 264). The theoretical background to this PhD study – symbolic interactionism – holds that social interactions provide resources for the construction of our sense of self. The findings demonstrate that interactions with health care professionals at the point of diagnosis and treatment have a key influence over a patient’s sense of self at a critical moment. This moment displays tensions that have implications for the self care agenda, which relies on the concept of patient-as-consumer and its implication of self-responsibility^(113, 265). The expectation that the patient should be a critical consumer is in conflict with paternalistic versions of care that some patients still expect – the notion of the well behaved or “good” patient accords with this (see section 7.2.1). Tension also arises between the perceived generalisation of patient experience in professional talk and the patient’s need to individualise their experience.

For participants in this study, personalised care was more to do with the style of a consultation than its content. Depersonalisation was perceived where oncologists failed to make eye contact, did not use the patient's name, and/or dismissed symptoms of treatment as only to be expected – factors which “discredited” the self⁽¹⁸⁰⁾. A feeling that care is personalised emerged from an acknowledgement – and display of trust in – the patient's descriptions of their experiences, and from the active inclusion of family members in consultations. The literature review for this study did not include papers exploring treatment consultation, but this interaction emerged as emotionally significant during the interviews. Explorations of patient–professional communication demonstrate that the time available in consultations can mitigate against these personalisation processes⁽²⁶⁶⁾ – but also that the benefits of involving family members far outweigh the challenges⁽²⁶⁷⁾.

Participants displayed a perception that information in consultations and leaflets was highly generalised, describing their bewilderment at worst-case-scenario descriptions of potential outcomes that did not fit with their expectations of a good prognosis. Those who were aware of their role as a “consumer” linked these descriptions with a fear of litigation among professionals (should difficult outcomes occur), and with an investment among charitable organisations in portraying the “cancer-as-life-threatening” story as a way of provoking support. Previous literature suggests a potential misunderstanding here – that health care professionals feel an obligation to describe all potential scenarios to patients to fully inform them, and to enable their participation in decision-making about treatments⁽²⁶⁸⁾.

Patients responded to this generalised view of treatment by looking for ways of personalising their situation and retaining a sense of self – a process documented in the existing literature^(136, 160). This manifested in a search for pre-existing psychological resources in response to past difficulties. During treatment and directly afterwards, identity was perceived as a stable resource, rather than in need of reconstruction. Most participants described positive attitudes such as strength, resilience and pragmatism as inherited characteristics – creating a reassuring “rhetoric of self”^(269, p311) which implied an innate ability to manage their situation. With the exception of three retired participants who associated physical discomforts with their

age, participants associated their symptoms with treatment rather than their disease. This demonstrates a crucial difference from most experiences of chronic illness, in which the debilitation introduced by persistent symptoms, according to Charmaz⁽¹⁸⁰⁾, can assault the self.

10.3.2 Disclosure and audiencing

Participants found that disclosure had to be actively managed. This concept is also described in Charmaz's work on chronic illness⁽²⁷⁰⁾. For Charmaz's participants, disclosure happened in two ways – it was spontaneous, where emotion spilled out with the telling, or protective, where the news was controlled and softened and the emotion put to one side to make it easier for others. In chronic illness, strategies for telling can develop over time and be used to maintain an advantage – for example, by invoking support through the creation of guilt.

Studies of disclosure demonstrate that the decision to withhold information about illness can be more marked in cancer than in chronic illness – it can be seen by the patient and those around them as stigmatising^(269, 271). In this PhD study, disclosure was managed in the moment, taking on board the reactions of others and deciding which responses were comfortable and which were not. Crucially, good prognoses allowed a reason for not telling. What felt comfortable varied across individual participants – for example, Gill (BC) disclosed her cancer on Facebook to invite enquiry, Laura (BC) withdrew from Facebook to prevent having to deal with responses on social media. For prostate cancer participants, disclosure was more likely where sharing advice was a likely consequence (reflected also in Gray *et al*⁽²⁷¹⁾, but only among the younger men). The two participants who shared their diagnosis least (both men) felt that disclosure was a pointless request for help that would elicit no response.

All participants were conscious that disclosure brought consequences – that while health care professionals managed the physical aspects of their cancer, they would have to manage the social ramifications for themselves. The perceived mutual exclusivity of support versus sympathy was a novel finding – sympathetic responses required emotional work from the patient, and were construed as unsupportive; empathy, curiosity and humour were well received. Female participants reported

limiting disclosure by maintaining their pre-cancer appearance – although they described this as a fundamental drive to maintain normality, rather than as the “game face” described by Beatty *et al*’s breast cancer participants^(137, p338) (seen in negative terms as a pre-requisite for receiving support).

The focus of this study on material resources demonstrated ways in which disclosure was actively managed. Participants made choices about the size of their audience through their use of social media, managed appearances via video phone calls, and controlled their level of engagement in verbal interactions by using e-mail and texting on mobile phones. These tools were used by younger participants, and by retired participants who were not struggling with other health issues and still enjoyed active involvement in social networks.

10.3.3 Transition at the end of treatment

The study findings demonstrate that at the point of treatment completion, patients can feel confusion over what is required of them in terms of taking responsibility for follow-up. This confusion can begin when discharge appointments specify the timing of a subsequent specialist check-up, and contact from secondary care at the specified time does not occur. Timing was particularly significant to prostate cancer participants, who had to request blood tests from primary care prior to check-ups. Most participants felt uncomfortably positioned with a foot in two camps (secondary and primary care) in the months after treatment. The expectation of information exchange behind the scenes was not fulfilled: this supports existing literature exploring patient–professional communication during transition^(82, 272).

Fifty per cent of the participants did not visit their GP at the end of cancer treatment. None of the participants who did visit their GP perceived their follow-up visit as developing a formalised care plan. Primary care was seen as lacking in expertise in cancer care, which also supports concerns in the existing literature^(59, 273). Among older participants in this study, the family GP was construed as part of family biographies in their earlier years and contrasted favourably with present day primary care, which was described as difficult to access and lacking in continuity. In contrast with previous research^(134, 136, 152), clinical nurse specialists were not prominent as part of the

professional support structure after treatment for participants in this study. Participants felt that they were recovering well, and minimised or devalued their need for nursing support. This viewpoint – that their experience of cancer was not severe enough to warrant continued support – also extended to their perception of survivorship support groups as an intervention more suitable for people who had more extreme experiences of cancer to share.

10.4 How might meaning-making shape people’s experiences in the year beyond treatment?

In talking about the meanings associated with cancer, participants offered surprisingly few metaphors. To Eleanor and Tony it was a turn or a curve in life’s journey, or a “funnel of difficulty” (Tony), to Ellie it was a “mire”. To Tony and Ellie, curatively treated patients skimmed the top of the funnel or the mire and made a quick escape – cancer did not grasp them by the ankles and hold on to them in the way that it might in more severe cases of the disease. Making meanings in this way helped participants to sketch out the future, or a range of possible futures, although uncertainties about recurrence led to futures sketched out in pencil rather than ink. This section will examine how social resources offered grist to the mill of meaning-making as participants moved between the social worlds of the family, the patient collective and the workplace. These meanings led to an admission of the changes brought by cancer (for example, within relationships, or at work), and the adjustment of behaviours to accommodate these changes. It then explores how participants created a new framework of interpretation around people who have been treated with curative intent, distinguishing themselves from “survivors” living through more extreme experiences of the disease.

10.4.1 Social worlds and meaning-making

Shibutani⁽²⁴¹⁾ and Charmaz⁽²⁶⁴⁾ point out that appropriate ways of behaving are socially defined, and that the meanings we make from our experience are sourced from reflection on our interactions with others. The social worlds we belong to make a range of perspectives available to us for the interpretation of our circumstances, and

oblige us to fulfil different roles and meet different expectations. The three most dominant social worlds in participants' accounts were the family, the world of cancer patients (the patient collective), and the workplace. A sense of belonging in these worlds allowed participants to exercise alternative identities, and to contextualise their experience through considering the perceptions and situations of others.

10.4.1.1 Families and friendship

In agreement with much of the existing literature, participants positioned family as their key social resource. The stressors of family life reported in other studies^(128, 152, 153) were absent from their accounts, with the exception of participants whose family support was more infrequent. Rootedness within a family hierarchy, and the domestic and supportive roles that became available through family dynamics, provided a pre-existing identity that participants could hold on to. This identity was reinforced through family celebrations, which consolidated family membership and strengthened family networks, bringing a sense of continuity behind the disruption of illness.

The majority of the research considered in the literature review approached family as a subcategory of social support, rather than a self-contained system with dynamics that are fundamental to adaptation. One paper provided an exception: this PhD study supports Illingworth *et al*'s description of the calibration of wellbeing between family members⁽¹⁴⁴⁾. Family histories helped participants to measure the scale of their problems and the strength they possessed to deal with them, and family activities obliged participants to work towards maintaining family balance in a way that is more overtly described in studies of cancer experiences in Chinese society^(151, 160, 163).

The counterpoint to this dynamic was the isolation experienced by participants who had little contact with close and/or extended family. The impact of extended family support cannot be underestimated, particularly in the context of the difficulties participants had in defining community, and the displacement experienced by those who had moved away from locations that had been familiar to them throughout their lives. In this PhD study, families had more to offer participants than friendships. Family contact was less conditional than friendship support – as described in the findings

(section 9.2.2), cancer could lead to a renegotiation of friendship boundaries. This is touched on little in the literature – Beatty *et al*⁽¹³⁷⁾ was the only paper to consider friendship ties in its analytic framework. Considerations of social support in the literature do not go far enough in examining the dynamics of non-familial relationships, and how support might be facilitated for people who are socially isolated. Adapting to cancer works best where it is a cooperative effort, and how best to create this around patients who do not have family support is yet to be fully explored in the literature.

10.4.1.2 The patient collective

Regularity of contact between patients in oncology waiting rooms proved to be a valuable resource for meaning-making for participants in this study, but this is not fully explored in the literature on the year after cancer treatment. The experience of the patient collective varied between cancer types – it was strongest between prostate cancer patients, developed around the protocol of drinking water in preparation for radiotherapy sessions; this allowed tacit identification of other prostate patients and provided a conversation opener. Prostate participants described the radiotherapy clinic as a “club”. Radiotherapy involved being allotted to a numbered machine, and this provided a basis of conversation for prostate and colorectal participants.

Prostate cancer patients shared characteristics in a way that breast and colorectal patients did not – they were more similar in age and lifestage (over sixty, mostly retired). Older breast cancer participants often equated a level of luck with encountering cancer later in life, in comparison with younger patients in clinic waiting rooms – camaraderie developed around older patients who were seen as having more life experience. Colorectal cancer participants reported little conversation based around the process of radiotherapy itself – equipment for internal radiotherapy could be recognised as it was taken to treatment rooms, treatment was invasive, and could be embarrassing and difficult to talk about. This nuance in experience reduced the benefits of the patient collective for colorectal participants. Literature taking a patient-centred perspective on radiotherapy is limited⁽²⁷⁴⁾, and could help to explore ways of reducing difficulties for colorectal patients.

The support of the patient collective was time-limited, received during periods of hospital treatment, but a highly salient contribution to the meanings made by patients about their own situation. The effects of clinic camaraderie kick-started the social comparison processes which previous cancer literature has shown to be a strategy for adaptation⁽²⁷⁵⁾. While experiences of cancer within the family can be a source of fear (they are most often historical, and as a consequence have often involved loss), real-time experiences of cancer in clinics suggested to participants that they were better off than other people with cancer. Participants perceived present day treatments as more effective than those recorded in family lore, and encounters with other patients provided a corrective to expectations of loss implied by family histories.

It is important to note that other people's experiences of cancer were not the sole source of comparison for participants – thirteen participants described comorbidities, other acute health problems or life difficulties as having had more impact on their life than their cancer treatment. Cancer was consistently placed lower down the ladder of difficulty than comorbidities. The literature reviewed for the project did not consider comorbidities as a distinctive category of experience, with the exception of Palmer *et al*⁽¹⁴²⁾, who acknowledge that health-related goals can be determined more by comorbid conditions than by the effects of cancer, particularly in older people. In this study, other life difficulties – for example, being a carer for a spouse or adult disabled child – were interpreted as more fundamental than cancer, reflecting the concept of illness and hardship as expected aspects of life^(88, 119).

10.4.1.3 The workplace

Five of the breast cancer participants and three of the colorectal cancer participants were still working. This was too small a percentage of the study sample to examine the return to work in detail in the analysis, but there were similarities in the data with existing research. The two participants who worked for larger institutions were discouraged from maintaining contact with work, and felt cut off from their work identity during their sick leave. They reflected issues reported in the literature – feelings of stigma associated with their illness, loss of confidence as their professional development was seen as compromised (both had to retrain on their return to

work)^(140, 173), and the loss of the companionship and structure that work provided⁽¹⁷³⁾. Like Lilliehorn *et al*'s⁽¹⁷²⁾ participants, they felt discouraged by the response of their workplace to their situation, and questioned the sustainability of the stress levels that had previously provided motivation at work.

Six other participants in this PhD study took sick leave during treatment – four perceived a high level of support from colleagues who knew them well. Those who worked in supportive, person-centred organisations were able to keep in touch with colleagues during their treatment; their experiences support the literature linking work contact to increasing cancer patients' sense of purpose and reducing feelings of isolation^(140, 161, 173). Their experiences contrasted starkly with those of the two participants working in larger institutions, suggesting that nuances in workplace culture affect the return to work as much as stigma and functional issues. Self-employment brought different issues to the fore – self-employed participants exercised a high level of control over disclosure, concealing it where possible to minimise disruption to their work.

A novel finding in this study was the continuing salience of work identity among retired participants as something that allowed them to be witnessed and valued. They sensed the loss of their work identities keenly, and referred to their working lives in interviews to explain their sense of self. Voluntary committee work continued to provide a sense of identity for three retired participants, but was contingent on good health prior to cancer treatment, the ability to be active, and enough freedom from other responsibilities to invest time in activities outside of the domestic sphere.

10.4.2 Redefining categories of “survivorship”

The differences between acute and chronic conceptualisations of illness are keenly perceived in patients who have been treated with curative intent. Participants in this study perceived those who had been treated with curative intent as a distinct category of people living beyond cancer, and developed a framework of meanings that worked towards carving out this niche. The term “survivorship” was rejected by most participants as a term that did not suit their situation.

10.4.2.1 Cured versus chronic

Winterling *et al*'s⁽¹²⁴⁾ study of curatively treated cancer patients demonstrated that the role of patients' expectations affect perceptions of recovery – a mismatch between expectations and experiences in the year after treatment can make recovery seem “tough”^(p589). Their male participants “took for granted”^(p588) that they would recover, and this attitude was associated with a smooth recovery. Complex expectations could make adaptation more difficult. In this PhD study, the worst-case-scenario communicated to patients by health care professionals presented complex expectations that participants rejected in order to adjust to their new circumstances. The anticipation of recovery among both male and female participants was closest to Winterling *et al*'s “taken-for-granted” approach⁽¹²⁴⁾.

Two key issues were associated with the concept of curative treatment in participants' accounts: first, the questioning by self and others of the validity of their cancer experience in comparison with that of other cancer patients; second, the maintainance of the notion of cancer as an acute episode as a way of navigating the curve thrown into the biographical pathway by the disease. Participants felt unable to lay claim to experiencing a life-threatening disease – this concept did not appear in the reviewed literature. They described a sense of fraudulence – a mismatch between the “cancer” label as it was perceived by others and an experience of illness that had been less severe than they had anticipated. There were contradictions in the data – when friends and acquaintances told them that they looked well, this was interpreted as a failure to acknowledge their illness. Others often (not always) expected them to recover rather than adapt – to live up to the idea that cancer was an acute episode; this deflected anxiety during social interaction, but was experienced as a frustration.

Among colorectal cancer participants, where symptomless cancer was discovered through screening, participants expressed difficulty in believing their diagnosis, and took treatment on trust. This phenomenon appeared in only one paper in the literature review – Ohlsson-Nevo *et al*'s⁽¹⁴⁸⁾ colorectal cancer patients found a smooth recovery unnerving – it left them wondering whether their cancer had been real, and unable to determine whether they were well.

Charmaz⁽²⁶⁴⁾ points out that adaptation to chronic illness involves the acknowledgement of impairment, and the data for this PhD study demonstrates a tension between the ideas of adaptation and recovery. Participants actively resisted the concept of chronicity – and found that this resistance was sometimes useful in talk with other people, who saw cancer diagnosis as entry into a permanent state of uncertainty about wellbeing. The conceptualisation of cancer as acute was also a way of moving beyond the change or curve it introduced into life and visualising recovery. Imagining recovery occurred alongside behaviours that implicitly suggested adaptation, such as the acknowledgement of the possibility of cancer recurrence, the renegotiation of relationships and the reassessment of the significance of work.

Participants talked about medical progress in cancer treatment and outcomes as a way of distancing themselves from the life-threatening aspects of the disease. They also reflected on their mortality, but associated these reflections with a reconsideration of their humanity rather than their encounter with cancer. This nuance of interpretation allowed them to expand their biographical timeline into the future in the same way as people who had not experienced cancer. When considering physical wellbeing after treatment, motivations for healthy behaviour were based on returning to pre-cancer activities – for those who perceived themselves as healthy before their cancer, treatment was viewed as a break from the healthy norm rather than a motivation to change their lifestyle. For those who were experiencing the physical effects of ageing and comorbidities, potentially curative treatment for cancer was not perceived as a central concern or a catalyst for behaviour change – where older participants were experiencing a “disintegrated life situation”^(167, p399), the chronicity of these circumstances overshadowed the perception of being cured.

10.4.2.2 “I’m not a survivor”

Definitions of survivorship in research, patient advocacy and the public domain, were not a good fit for participants in this study. The findings support previous research questioning the usefulness of the term^(69, 70, 86, 136, 137). Participants considered themselves a unique category of cancer patients who had been lucky with their diagnoses – fifteen of the participants used the word “luck” in comparing their cancer

with that of other people. Luck in connection with cancer type and severity was a concept reported in six of the literature review studies – by individual participants^(134, 136, 162), and as an overarching concept^(133, 151, 152). In the year beyond treatment, the perception of luck played a role in setting optimistic expectations about recovery.

Sontag's⁽¹⁰¹⁾ prediction of the loosening of the association between cancer and death alongside improvements in treatment is not reflected in this PhD study. The possibility of death is still intimately connected with survivorship – its perceived removal by treatment with curative intent makes the “survivorship” label difficult to subscribe to. Participants' doubts about the validity of their cancer experience and retrospective reflections on treatment as presenting few difficulties led them to feel that they did not deserve a label suggesting that they had overcome a life-threatening disease. Expectations that cancer would be a crisis had not been met, and favourable comparisons between their own situation and that of other cancer patients reinforced this view. Most participants side-stepped the issue of benefit-finding as a response to the cancer experience, suggesting that their experience had not been extreme enough to provoke fundamental changes in their lives.

A minority of female participants were more equivocal, defining survivorship in statistical terms in the same way as their oncology consultants: for these women, survival was a term that they felt they might qualify for two or five years beyond diagnosis. Information about risk helped participants to better define their situation, but only arose in a minority of participant accounts. This supports recent policy literature calling for more consistency in the communication of levels of risk beyond treatment⁽²⁷⁶⁾.

Treatment with curative intent forms a subworld⁽²³⁹⁾ within the survivorship arena. Membership is determined by the person with cancer through comparing themselves with cancer patients who are suffering in ways that they are not. Membership cannot be legitimised by their consultant, because cure cannot be guaranteed. In seeing other people with more problematic manifestations of the disease as more deserving of follow-up support, and in sensing an investment in the concept of cancer as life-threatening in normative discourses of survivorship (including those of charitable organisations), they perceive uneven competition for follow-up resources within the

survivorship arena. Their lack of visibility as a distinct category leaves them in an uncertain position in relation to follow-up care.

10.5 How do people make use of everyday resources to adapt to life in the year beyond treatment?

A chief focus of this project was to explore the ways that material objects and spaces in local environments were used by participants to help themselves adapt to life after cancer treatment. Analysis suggested that everyday resources were used to achieve three objectives: control, comfort and continuity. These concepts arose in the previous literature, but were subsumed by other aspects of cancer experience. Rather than exploring comfort, much of the literature focuses on physical discomfort – where comfort is briefly considered, it is facilitated by good communication with health care professionals^(134, 147, 168, 188), family relationships^(138, 149), and religious faith^(145, 177). Continuity was connected with the structure brought to life by work⁽¹⁷²⁾, or discussed in terms of continuity of care^(134, 142, 166). Where maintaining or regaining control is discussed in greater detail, it is interpreted through the lens of cognitive strategies^(136, 166) – in particular, patients’ abilities to exercise agency^(137, 143).

Three papers investigate these concepts in more depth. Lagerdahl, Moynihan and Stollery⁽¹⁵³⁾ present control as a subtheme, under which they briefly outline the lack of control brought about by cancer (a phenomenon referred to briefly in much of the literature^(129, 137, 139, 162, 167)). Picard *et al*⁽¹⁴⁹⁾ connect the construction of meaning with continuity and hope, and under this theme discuss the significance of re-establishing continuity between a patient’s past, present and future, but do not relate this to theories connected with biography. Cayless *et al*⁽¹⁶⁵⁾ examine continuity and discontinuity by exploring the projection of disrupted futures among men with prostate cancer, setting the theoretical scene with Bury’s⁽¹¹⁶⁾ theory of biographical disruption.

The findings of this study depart from the focus on supportive care and cognition. The analysis examined how participants made use of material and environmental resources (Clarke’s “nonhuman” elements⁽²³⁴⁾) to regain control, create comfort and chase

continuity. The study frames material objects and aspects of the local environment as resources for adaptation. Participants made use of whatever was at hand, regardless of their social status or economic power. Only two papers in the literature review briefly touch on similar issues. Landmark, Strandmark and Wahl⁽¹⁶⁷⁾ describe how enhancing everyday contentment through items such as books and music recordings increased patients' levels of comfort. Beatty *et al's* study⁽¹³⁷⁾ describes the significance of wigs and scarves in ceremonies of closure after chemotherapy. Each of the following sections describe the conditions that motivated action towards regaining control, creating comfort and chasing continuity; these are followed by examples of the domestic and community resources harnessed to facilitate adaptation.

10.5.1 Control

The loss of control brought by diagnosis was most keenly expressed in the frustrations of sitting out the “Tick-tock/tick-tock/it’ll-happen/when-it-happens/if-it-happens” (Eleanor, BC) of hospital waiting times. This was experienced as a slowing force that merged into the physical fatigue experienced after treatment (a phenomenon similar to the slowing of pace experienced in chronic illness⁽²⁷⁰⁾). Participants chose to scale back the pace of life as they took the curve thrown by the disease, but the force that pulled life straight was a nagging drive to be active. This tension between the short and the long term was difficult to reconcile, and they began looking for objects that would help them to live with treatment symptoms, rather than wait them out.

Harriet used a kitchen timer to control periods of sleep during the day; Arthur “got the bottle” to go out in the car again, using a plastic urinary bottle to manage bladder problems. Derek felt trapped by his stroke rather than the effects of his cancer treatment (which had begun to abate), missed walking his dog and talking to people in his local community, and focused on using his mobility scooter to get out of the house and enjoy social contact. Photographs of cars, bikes and mobility aids introduced the significance of recovering mobility into the interviews, and were associated with regaining independence.

Marking achievements, past and present, provided reminders of participants' self-efficacy. James had certificates of his literacy achievements on his wall – his house was

decorated with paintings he had created, some of which had been submitted to galleries; for her second interview, Lesley photographed medals she had won recently for marathon running. Finding ways of maintaining hobbies reminded participants of who they used to be, and who they still were. Arthur surrounded himself with model-making equipment in his busy shed. Creating new projects, from shed construction (Fiona) to decorating your lounge (Gill) to laying a garden path (Jack) or decluttering the house (Laura), provided distraction from difficulties, helped to chart small steps of progress and re-establish feelings of control. A sense of disjointedness could arise where hobbies had to be put to one side.

Hobbies were a resource for the act of planning. Making plans worked towards projecting the biographical timeline into the future: creating a vision of the path ahead (imaginary or otherwise) gave participants a feeling of purpose – and of the possibility of regaining control by picking up life’s previous pace. The marking of celebratory dates with cards or flowers could be a reminder of a ladder of significant events stretching into the future. The simple act of filling in a diary (photographed by Eleanor and Janet) forced participants to think ahead. A card referring to cancer (described only by Laura) could not provide this future orientation. Retired participants who were able to plan ongoing voluntary work with community groups maintained feelings of connection and capability, but this required a level of physical health and independence that was not open to all older participants.

10.5.2 Comfort

The psychological and physical discomforts of diagnosis and treatment were combatted by participants with small acts of hedonism. Short term pleasures and the reassurance provided by familiar environments took on greater significance. The use or display of personalised objects reinforced participants’ sense of self – an “owned” chair in the lounge, a personal mug for tea or coffee (chemotherapy often temporarily removed the pleasure associated with tea and coffee), or items that participants had created such as models, wood carvings or paintings. Favourite food and drink appeared consistently in photographs – after disruptions to taste or digestion during treatment, the rediscovery of this pleasure was a test of recovery.

Gifts also brought comfort, although the interpretation of the written word in cards could sometimes present difficulties or highlight misunderstandings. This potential was diluted or removed by the giving of objects. The perceived personalisation of gifts could heighten their significance – where they were hand made (Derek’s paper flower), tailored to participant’s needs (Eleanor’s heart-shaped cushion for physical support after breast surgery), or symbolic (Liz’s lilies – her wedding flower). They could also be a source of humour (Ellie’s £50-note toilet paper), which some participants used as a way of reducing the intensity of their situation.

Comfort also came from the displacement of difficult thoughts – while this was recognised as a short term strategy, participants were keen to stress that this was a better option than spending energy dwelling on their situation (this could include spending energy working out longer-term strategies for recovery). Methods of escape included diverting the imagination through reading or creative tasks, and spending time in familiar indoor or outdoor spaces that encouraged quietness and calm. Existential concepts in the literature dovetail here – creativity and pleasure were interpreted as ways of challenging the anxiety of meaninglessness^(167, 175). Comfort came from the practice of “safeguarding zones of wellbeing”^(149, p123). A further grounding force was spirituality: two participants photographed churches, representing the comfort of fellowship. Spiritual comfort was sensed in a secular way in outdoor surroundings by participants who were not religious.

One further “nonhuman” resource was associated with comfort by participants: domestic pets. This could be construed as a social resource, as animals inspire emotional bonds and increase contact with other human beings⁽²⁷⁷⁾. In this study, pets provided company and reassurance – and for three participants, an intuitive recognition of illness. The loss of previous pets was explored, and their replacement viewed as a necessity – they were seen as intimately connected with wellbeing (rather than health), not only for their role in encouraging exercise, but for their unconditional companionship. Bonds with pets were stable in a way that human relationships were not; they did not fluctuate in emotional intensity during the course of illness, or require renegotiation afterwards.

10.5.3 Continuity

Everyday activities establish what is normal, and their loss comes alongside a loss of self^(160, 164), social contact and sense of purpose. For example, when work cannot resume in the same way as before treatment, everyday life becomes unrecognisable⁽¹⁷⁵⁾. The introduction of unfamiliarity into the everyday by cancer disrupted participants' sense of self and life plans, and they worked hard to resist this by finding alternative ways of emphasising continuity in the months after treatment. The re-establishment of domestic roles and routines formed part of this process – a way of restoring a sense of self reported in existing literature^(136, 173, 182). In this study, it was clear that maintaining roles and routines relied on the cooperation of others – attentive caretaking or encouragement of the sick role⁽¹⁴⁶⁾ could prevent the person with cancer from taking part in their usual activities.

The preservation of continuity was sometimes consciously outward-facing – for female participants, adjustment happened behind the scenes while efforts were made to present their usual physical appearance after treatment. This was helpful in interactions with others, but did bring tensions, as illness could pass unacknowledged. A predominance of female participants maintained visibility on social media and via video phone calls as a means of maintaining existing emotional connections with other people. Male participants were driven towards maintaining a more global sense of connection, preferring to use the internet to remain connected with hobby groups or keep abreast of politics and current affairs (two male participants photographed their television, stating its salience as a means of staying in touch with the wider world).

Participants most often chose their lounge as the venue for their interview, and in eleven interviews, indicated family photographs in the room as they talked (the photo elicitation method encouraged this consideration of images). Data associated with family photographs indicated their salience as markers charting inherited characteristics and celebratory events, and memorialising lost family members. Birthdays and anniversaries characterised family biographies and shaped “future memories”^(14, 80) – the imagination of events to come. Mementoes of past events (including celebratory cards) reassured participants of their place in a continuous family timeline. This reflects the significance of memories as representations of the

“familiar past” in Charmaz’s theory of chronic illness^(278, p233-4). For those who were socially isolated, family photographs could be more associated with loss and disruption than continuity – their significance was only beneficial where supported by social contact with family members. Interaction was key to warding off biographical disruption⁽¹¹⁶⁾ – in this study, among retired participants who reported low levels of social contact, illness and ageing had begun to steal away anticipated biographies.

10.6 How might demographic characteristics mediate experiences of adaptation and recovery?

Purposive demographic categories such as gender, age and economic status were not the main focus of the analysis for this project, but divergences in the data related to these issues were flagged as they arose in the findings chapters. During analysis, it became clear that the design of the project placed limitations on their exploration – the sample was small, and further subdivisions of the data would have led to a lack of depth in the analysis. A second caveat is that gender conflates with cancer type in much of the data – breast cancer participants were all female, and prostate cancer participants male. Age, finance and employment status were inextricably interwoven, and could not be interpreted in depth as individual concepts. Having explained the limitations of answering this research question, this section brings together the sparse data connected with the demographic characteristics of the sample.

Changes in relationships with others were reported mainly by breast cancer participants – and consequently, more by female than male participants. Female breast and colorectal cancer participants talked about their efforts to maintain or recreate their previous physical appearance to others after treatment – this theme did not arise in interviews with men. Areas of dialogue unique to male participants included a fascination with the mechanics of radiotherapy machines. Among prostate cancer participants, men demonstrated a drive to pass on advice about the details of treatment to other patients that was absent from the accounts of female participants (reflected in one other paper in the wider literature⁽²⁷¹⁾). Both male and female participants in this study saw dwelling on their illness as an unproductive exercise,

unlike McCaughan *et al*'s study⁽¹⁷¹⁾, in which the female participants were more likely to dwell on their cancer than the male participants.

Older participants saw both the benefits and the drawbacks of ageing. Age brought greater pragmatism about the approach of death, and this was perceived as decreasing worries. Retired participants were more likely to put physical symptoms down to ageing, younger participants were more likely to worry that unexplained aches and pains after treatment may be related to cancer. For the sample of participants in this study, age brought financial security – six retired participants talked about having paid off their mortgage, and having pensions that kept them financially comfortable (two of these participants lived in deprived areas). Most had enjoyed long term employment in the same job, reflecting a different *Zeitgeist* to that experienced by some of the younger participants who felt the loss of pace with working life during sick leave keenly. Most employed participants questioned their level of investment in their work identity as a result of their cancer experience.

Constructing anticipated biographies as a way of orienting to the future became more difficult when age, comorbidities and/or caring duties for other family members created other disruptions. Making plans (such as travel) involved financial investment and often, the willing commitment of other family members. One marked difference between participants living in the most deprived areas and those living in affluent areas was the social contact available in the local community. Participants living on estates in less affluent areas had lived their whole lives in the same area, and were embedded in long-standing and supportive social and family networks that were not available to participants living in more affluent areas, or participants who had moved towns during the course of their adult life.

Interpretation of the influence of culture in the entirely white British sample is restricted to the ways that Western cultural discourses surrounding cancer, described in Chapters 1 and 2, were used in meaning-making (see *Laying down the lore*, section 8.3). There is a suggestion, however, that the collaborative family response to cancer in this study (see section 8.2.1) may have some similarities with the family dynamics described in studies based in Asia^(151, 160), and this suggestion is supported in the literature review by Illingworth *et al*⁽¹⁴⁴⁾.

10.7 Chapter summary

This chapter began with an exploration of the limitations of the research project, and how these were reflected in the analysis. This builds on earlier discussions of the limitations of the methods, explored in Chapters 4 and 5. It examined the difficulties of specifying exact timepoints for interview in qualitative studies of the year after cancer, and how similar difficulties are evident in previous research. It also discussed how an examination of the role of demographic characteristics in the data was compromised by the pace of recruitment and the nature of the study sample. The research questions were then addressed.

Key concerns of patients at the end of treatment include the personalisation of care and how this was or was not achieved, the management of disclosure and how this was affected by context, and the unexpected frustrations of integrating secondary and primary care around their needs. Meaning-making shaped their experience beyond treatment through the social worlds of the family, other patients and the workplace. The actions of others in these worlds could reinforce or destabilise their sense of self, provoke the reassessment of priorities, and help them to compare their cancer favourably against the cancers experienced by others. The majority of participants redefined “survivorship” as a category that did not include the curatively treated. Expectations of recovery were high, and away from the gaze of professional care, everyday resources in the home and local environment were harnessed to re-assert control, to create short term feelings of comfort and wellbeing, and to suggest longer term strategies for recovering a sense of continuity in life. The chapter closed with a reflection on the role of demographic characteristics in adaptation.

Chapter 11: Conclusion

It is, of course, likely that the language about cancer will evolve in the coming years. It must change, decisively, when the disease is finally understood and the rate of cure becomes much higher.

Sontag, 1978/2002^(101, p86)

11.1 Introduction

This PhD study investigated adaptation to life after cancer by people who have been treated with curative intent. It investigated “the active steps people take to achieve a level of normal life”^(184, p129), focusing on how people mobilise their everyday social and material resources to actively adapt in the year after potentially curative treatment. The *Conclusion* summarises the rationale for the study and the key issues raised by the research. It re-examines the role of theory in characterising the experiences of people treated with curative intent, and suggests that there are difficulties in the vocabulary we currently use to describe their situation. It then discusses the implications of the findings for health care practice, outlining current gaps in thinking in psychosocial care and how these might be addressed. The thesis comes to a close with a consideration of the implications of the findings for future research.

11.2 Study rationale and summary of the key issues

The rationale for the study emerged from recent initiatives in cancer care that recognise the diversity of experiences of living beyond cancer by stratifying pathways of follow-up. Patients treated with curative intent will be guided, where appropriate, to supported self management. Self management is the management by the patient of problems resulting from chronic or long-term health conditions. Addressing psychosocial needs also relies on self care – the actions taken by individual patients to maintain their health and wellbeing. Self management and self care take place in the home and community and rely on a complex range of issues, including the physical and social environment, and patients’ perceptions of their situation⁽³⁴⁾. The existing literature on cancer survivorship pays little attention to the contextual issues that

mediate the practice of self care in day-to-day life, and how the social and material resources outside of the medical arena might facilitate or inhibit adaptation to illness.

This study demonstrates that current ideas about how “survivorship” should be done fall short in acknowledging the subtleties in meaning that characterise the experiences of people who have been treated with curative intent, and the multiple contexts within which this experience plays out. For example, stereotyping patients by singular demographic characteristics such as age, gender, social status or cultural background, without taking into account how these issues overlap within each individual’s experience, can reinforce the unhelpful prescriptions for “survivorship” behaviour which exist in the public domain by creating expectations about how recovery might be managed. A focus on exclusive demographic categories can obscure the potential interactions between them within individual accounts: a phenomenon recognised in recent decades by intersectionality theorists^(279, 280, 281).

11.2.1 A role for intersectionality?

A description of how demographic categories appear across a qualitative data set does not explain how they intersect: intersectionality theory takes a step beyond this to ask how social categories overlap within individual accounts, and crucially, how these produce inequalities between individuals. Intersectionality theory has resisted clear definition, but Davis⁽²⁸²⁾ characterises it as the exploration of “the interaction of multiple identities and experiences of exclusion and subordination”^(p67). Research studies often draw on intersectional identities defined by broad categories such as race, class and gender, but recent literature acknowledges more subtle, multiple strands of differentiation based on social positioning^(283, 284) and how it is affected by “economic, political, cultural, psychic, subjective and experiential” dimensions^(284, p76).

It has not been the intention of this study of this study to focus exclusively on inequalities, and the cultural homogeneity of the sample (all white, and all born in the UK) imposed limitations on such exploration. There were differences between participants in age, gender and level of affluence, and section 10.6 explored the difficulties of separating out strands of analysis relating to these categories. Layers of difference or divergence were also reflected in what participants represented as

“other” in order to carve out a social position for the experiences of those who have been curatively treated (for example, others had more extreme experiences of cancer, others fitted the “survivor” label in the way that they did not), or to carve out their own position of difficulty or subordination (for example, others have better family support, others do not have mandatory duties as a carer).

There are clues in the data which indicate that people’s ability to self care is affected by intersections of experience related to such identities and social positions.

Intersections can be pinpointed, analytically, by looking for “hidden differences” between individuals^(285, p164), and by maintaining an awareness of social worlds and experiences of exclusion. The strongest clues to hidden differences in the data for this project touched on the dangers of considering marital status and affluence in isolation from other factors, which might affect the way that health care is offered. The examples of this offered below are not in themselves intersectional (they do not demonstrate extreme experiences of exclusion or subordination), but reinforce how identities implied by demographic characteristics should be considered in a flexible way. The notion of social patterning described by Williams⁽¹¹⁸⁾ (see Chapter 1, p16), describing a confluence of competing influences on individual experience, is perhaps a useful sensitising concept for such issues where intersectionality seems too complex.

Where people with cancer are married, in a domestic partnership or have frequent contact with family, this implies access to support^(133, 144-50). The data in this study demonstrates that this is not always the case. For example, when people experiencing cancer treatment have a pre-existing identity as a carer, this can take precedence over being cared *for*. For example, throughout chemotherapy and recovery, Janet remained the primary carer for her husband who had suffered a stroke and had prostate cancer. Janet felt that specialist nurses categorised her as white and middle-class, assuming a level of affluence and support that she did not have. James had remained a carer for his adult daughter, who suffered from severe mental and physical disabilities, throughout previous experiences of cancer, and although his daughter had been taken into a nursing home, abandoning her by dying remained a key concern.

In the quantitative literature, different levels of affluence are related to different cancer outcomes – deprivation is associated with higher mortality rates^(286, 287). The

geographical mobility allowed by a level of affluence is demonstrable within the data of participants (such as Pete and Stephen) who were drawn away from longstanding residential locations to follow their adult children to their place of employment in order to provide care for grandchildren. For Pete and Stephen, adult children moved on again, leaving them alone in a place that was not home. Pete found this isolating (Stephen, a sociable character, did not). In contrast, participants who lived in less affluent areas had lived on the same estate for the majority of their lifetime (for example, Mary and Derek), had built up a wealth of social capital, and enjoyed social support on their doorstep from family and non-family. Affluence also featured in contradictory ways in the accounts of retired and working participants. The accounts of retired participants contained multiple references to the financial security provided by life-long work pensions – a security that was missing from the accounts of younger participants, and will have implications for future cohorts of patients.

11.2.2 Developing a better sociology of survivorship for patients treated with curative intent

Survivorship is currently defined as “living with” or “living beyond” cancer^(288,289). These definitions fail to recognise the increasing diversity of experiences of people who have had a cancer diagnosis. Survivorship, if we define it as living beyond diagnosis, can be a chronic state where cancer or its symptoms persist or reoccur. For people living beyond potentially curative treatment with a good prognosis, chronic aspects of the disease will be minimal or absent – for this subworld of survivors, the reconceptualization of cancer as a chronic disease is not straightforward. There is a lack of fit between the predominant association of cancer with negative outcomes and the experience of living beyond primary treatment without being visibly ill. The difference between perceptions of chronic and cured were crucial to participants in the first year beyond treatment, and the sense that illness was acute assisted them in turning the curve thrown by the disease. Participants were not ready to acknowledge a state of chronicity, and saw their claim to the status of “survivor” as fraudulent.

Theories of meaning-making in chronic illness drawn on by the existing literature (existentialism, identity and biographical disruption – see Chapter 2) do, however,

provide a range of concepts that are helpful in exploring the experiences of people treated with curative intent. These are revisited in summary form below to explore implications raised by the findings of this study.

11.2.2.1 Existentialism

The existential anxieties which emerge from contemplating death, freedom, isolation and meaninglessness – applied explicitly or implicitly to cancer experience in the previous literature^(153, 161, 167, 168) – are concepts which can also provide a useful framework for adaptation beyond potentially curative treatment. Study participants were moved by their diagnosis and treatment to address their own existential anxieties.

During the first year after treatment, they recognised and reinforced their sense of belonging in social worlds – for example, maintaining links with the world of work, or allowing themselves, temporarily, to become part of the patient collective. This addressed some of the anxieties surrounding the loss of structure imposed by treatment. They undertook small acts of hedonism, spirituality or creativity (sometimes instinctively, sometimes deliberately and with effort), which increased the meaningfulness of life and gave a sense of purpose. This created an expanding chain or series of significant present moments. Making meaning from the anxieties of others (such as ruminations about their potential death or culpability) helped participants to carve out their position in the centre of their own cancer experience and take ownership of it. Existentialist concepts express why we need meaning, rather than how meaning operates (the perspective offered by cognitive theories). Becoming aware of *why* we need to make meaning, rather than breaking the meaning-making process down into its constituent parts, makes it easier to understand the behaviours that we might use to address our anxieties.

11.2.2.2 Identity

The literature reviewed for this project drew on theories of identity which have emerged from chronic illness research, in which people's experiences are characterised by a sense of a loss of self and a fracturing of identity⁽¹⁸⁰⁾. This emerges

from the physical changes which come with treatment, the disruption of routines which forces changes in familiar roles at work and at home, and the expectations implicit in public discourses surrounding cancer (see section 1.3).

Participants in this study held on to the prospect of cure, alongside an acceptance of the uncertainty of this. As a consequence, they rejected the idea of permanent physical change, attributing novel physical discomforts to cancer treatment rather than the disease, and at the point of second interview were still expecting these symptoms to subside. Most had not, in the course of the first year beyond treatment, acknowledged the possibility of permanent impairment that Charmaz cites as a feature of the response to chronic illness⁽²⁶⁴⁾. Loss of unity between body and self⁽¹⁸⁰⁾ was resisted. Participants displayed a marked ambivalence about the concept of cancer bringing personal change, and most rejected the “survivor” identity and (in talk with other people) the expectations engendered by the “cancer patient” label. After potentially curative treatment for a primary cancer, they were not ready to assume an identity defined by illness: cancer was positioned as something outside of the self.

Domestic and work identities embedded in roles and routines were the first aspects of self that participants acknowledged to be affected by cancer. Their response was to call on personal strengths from the past – inherited, or developed through earlier life experiences – to reinforce their sense of who they were at the point of diagnosis. This was reinforced by health care professionals who made consultations feel personal by making eye contact and acknowledging patients’ personal perspectives on their symptoms. In the home, participants who were supported to perform behaviours connected with domestic and work identities, such as walking the dog or meeting work colleagues informally, found adaptation easier. Maintaining responsibility for familiar tasks, despite having to adapt expectations to suit fluctuating physical capabilities, supported their sense of self.

With patients who have been potentially curatively treated, it is necessary to avoid the premature adoption of ideas about loss of self from chronic illness theory. It is also worth considering how research methods may affect the centrality of the self in data analysis: in Charmaz’s constructivist grounded theory, for example, coding with gerunds tells the story of the self by focusing on the first-person perspective. Clarke’s

situational analysis, added to Charmaz's techniques, encourages us to shift our viewpoint and take fresh perspectives (see section 1.4).

11.2.2.3 *Biography*

The effect of cancer on the biographical project of "self-realization"^(114, pix) is acknowledged by theories focused on biography. Lifecourse narratives are a key tool for reframing meaning and reclaiming authorship over life. The uncertainties brought by cancer threaten a loss of authorship^(86, 153), as the ability to predict or imagine the future is impaired. In this study, participants did describe disruptions to their lifecourse: these were negotiated in work and domestic roles, in relationships, and in functional abilities. Where comorbidity and aging conflated with cancer, this created particular contradictions, on the one hand demoting the cancer to secondary priority alongside other chronic conditions and bringing pragmatism and easier acceptance of illness, on the other severely reducing time-frames for notional futures⁽²⁹⁰⁾. This potential lack of time (a crucial resource for reconstruction) could be experienced as devastating rather than disrupting future plans – as Janet described (see p207), the vision of twenty years of single life after her husband's death evaporated in the face of her experience of cancer.

Most participants perceived the disruption to their biographies as short term – they were unwilling (at the point of completing potentially curative treatment) to categorise their illness as chronic. This did not preclude the acknowledgement that they may have to face learning to live with their disease in the longer term⁽²⁷⁰⁾. Maintaining a belief that their illness was an acute episode, alongside acknowledging the possibility of its return, provided an asset for recovery in the wake of potentially curative treatment. Martin *et al*'s⁽¹⁶⁴⁾ use of the term reconstruction offers a subtler way of conceiving the recovery experience, released from prescriptions for positivity, which allows for alterations to day-to-day life implied by the cancer-related concept of reaching a "new normal"^(7, 171).

The role of both past and future were crucial in the adaptive strategies of participants, supporting Barbour's argument that looking backwards is as important as anticipating what might be ahead when people reconstruct their biographies around health

events⁽¹¹³⁾. Looking towards the longer term, chasing continuity – making an effort to retain social connections, roles, routines and physical appearance during and after treatment – offered a way of maintaining the *feeling* of authorship over life, even where this manifested in ways which were only partially successful. Older participants who were relatively fit and functional could subscribe to the idea of continuity. Where comorbidities or caring responsibilities were prominent, a focus on family histories, and on personal characteristics and ways of behaving which had been constant throughout the lifecourse, could provide assets for chasing continuity in a way that actively planning for the future could not.

These issues reflect the importance of taking social patterning⁽¹¹⁸⁾ into account – for example, stage of life⁽²⁹⁰⁾ and other intersectional identities – when considering the effect of illness on a patients' lifecourse. They also demonstrate that disruption – a negative lens which highlights fractures and discontinuities – could be tempered by a focus on reconstruction. This can be approached by exploring experiences of success rather than distress in response to the difficulties of illness. Rather than producing generalised prescriptions for a positive recovery based on avoiding negative ways of adapting, we should look to describe success *in context*, revealing how structural constraints might combine in different ways around each individual and what might constitute success for a particular patient. At points when discontinuity brings “chaos”⁽⁹⁹⁾ and feelings of liminality are most prominent^(165, 185), the salves for anxiety and the present-moment focus offered by existential concepts (see above) might initially offer more scope for short-term adaptation than a focus on repairing the biographical timeline.

11.3 Implications for health care

The findings of this study demonstrate that misunderstandings can happen in the space between patients and health care providers. Information can be imparted to patients with good intentions, but received in a different spirit. For example, the communication of worst-case-scenarios, perceived by professionals as facilitating decision-making, can be perceived by patients as taking a stance to avoid litigation. Calling on statistics to inform patients about risk can be perceived as generalising,

rather than personalising, care. The need to “objectify, code and structure”^(278, p152) patients’ experiences to document them needs to be balanced with a sensitivity to their subjective experience. Helping patients to understand the reasons behind communication protocols, and balancing this with an acknowledgment of their subjective experience, has the potential to reduce misunderstandings.

Rather than conceiving of points along the cancer trajectory as being “teachable moments” which should provoke agency in patients^(10, 291), this PhD study suggests an attention to structural factors at these points, and how they might kick-start or inhibit patients’ feelings of control over their situation. The culture of chemotherapy and radiotherapy clinics is a potential, time-limited resource for camaraderie that can help patients to gauge progress and feel a sense of self-efficacy. Participants who did not wish to join group interventions after treatment were happy to talk with other patients during treatment. The shift towards self care after surgery and chemotherapy or radiotherapy does not equate with discharge from specialist follow-up, which comes two to five years after treatment. At the completion of surgery, chemotherapy and/or radiotherapy, participants in this study felt released into a liminal state with a lack of timely information about the responsibilities they could take for their own care.

11.3.1 Recommendations for survivorship policy and supportive care

The reconceptualisation of cancer as a chronic condition is forgetting one section of the “survivorship” population – people who have been potentially curatively treated who are not yet suffering from permanent, long term treatment effects which significantly impair their day-to-day life. While people who have undergone treatment with curative intent may later be diagnosed with secondary cancer, or a second primary cancer, curative treatment can provide a gap or clear space in their cancer trajectory which may or may not be permanent. It is inappropriate to expect people in this space to consider themselves as partially defined by a disease that they hope is no longer actively in evidence in their body.

Figure 30 (p267) outlines recommendations for policy and practice drawn from the findings of this study, which has considered people who have had potentially curative treatment. There are two overarching issues to consider, emergent from the analysis.

Firstly, participants saw themselves as a particular subcategory of people living beyond a cancer diagnosis, and most did not wish to call themselves “survivors”. It would be helpful to distinguish people treated for primary cancers with curative intent as a subworld of the population living beyond cancer. This would enable us to better envisage different needs at different points in the cancer trajectory.

Secondly, in participants’ narratives about their illness, self management required professional support and clinical resources in a way that could be clearly distinguished from the softer concept of self care. Self care comprised of actions participants took for themselves, using everyday resources, to maintain their wellbeing. Self management is naturally tailored to the health condition it addresses – its focus is the cancer, not the person. Where a recursive relationship is created between patient and health care professional, self care can be tailored to the person, using their everyday resources to create strategies for managing the effects of symptoms on day-to-day life.

11.3.1.1 Implications for self management

In order to establish the recursive relationship implied by the concept of partnership working^(37, 38), the allocation of responsibilities within a self management framework must be clearly and realistically explained to patients. For example, in this study, where follow-up consultations in secondary care were promised within a specific timeframe but appointment letters did not arrive as expected, participants experienced concern and confusion. Where GP practices needed to provide services to dovetail with consultations in secondary care (such as blood tests at specific timepoints in advance of consultations), the responsibility for this dovetailing, or joining up, often fell to the patient. Confusion could have been avoided by making the patient aware of this potential crossover of responsibility. If patients are given unrealistic expectations about their responsibilities, they will perceive that their needs are not being met.

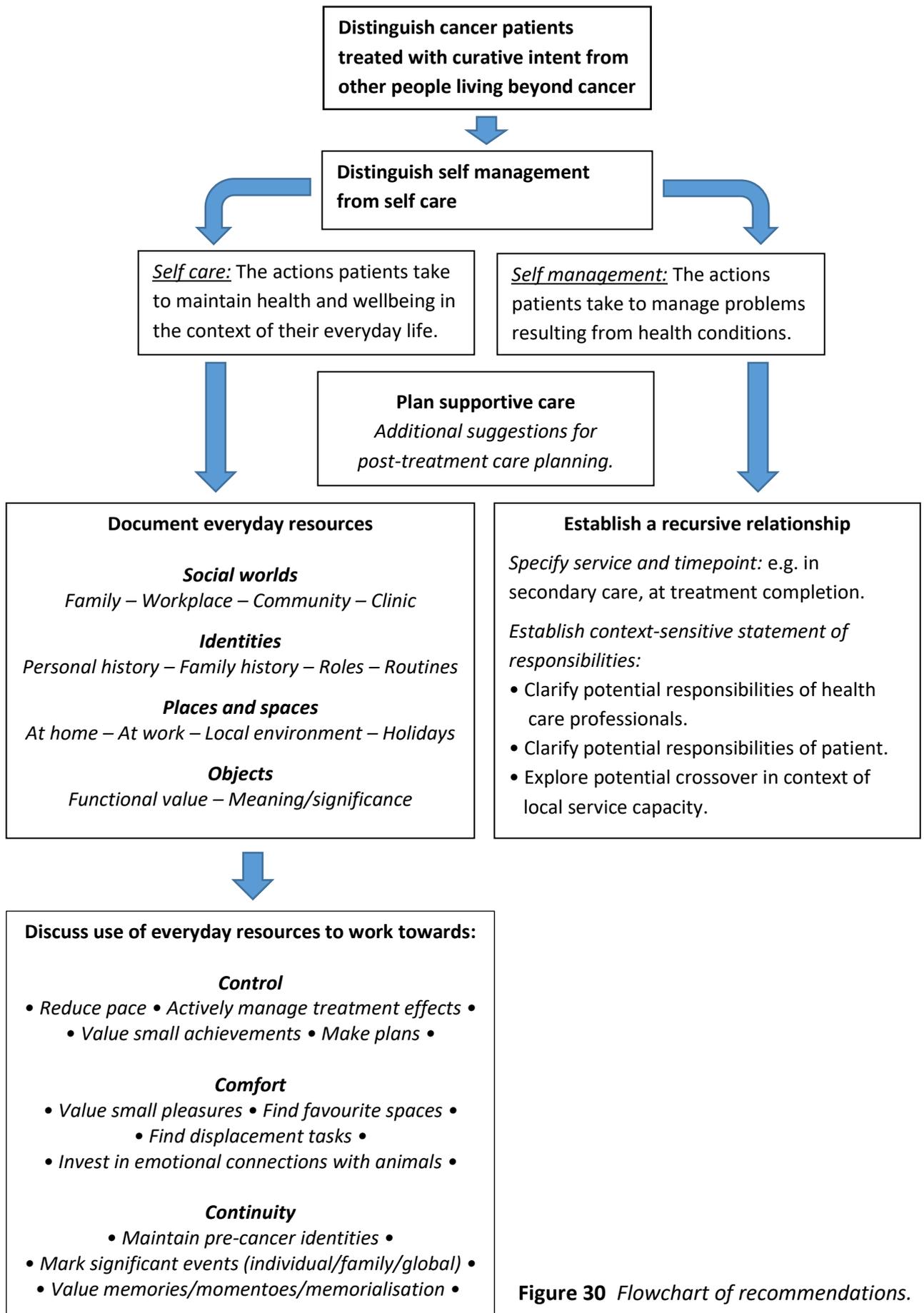


Figure 30 Flowchart of recommendations.

It is also imperative to be aware that patients who have had potentially curative treatment can feel uncomfortable about asking for further professional support at the point of treatment completion. Participants in this study minimised their need for psychosocial care, seeing themselves as less deserving of support in comparison with others with less “lucky” prognoses. However, patients who avoid proactively seeking help can perceive, retrospectively, a lack of support. If supported self management is the best way forwards, this has to be proactive rather than reactive, to avoid patients withdrawing from engagement with services.

11.3.1.2 Implications for self care

The current basis of psychosocial assessment in follow-up care focuses on documenting distress and concerns and signposting patients to agencies external to the health service that they can approach for assistance. The findings of this PhD study demonstrate that some patients might avoid seeking help from external agencies if they judge themselves as having a lower level of need than other patients. It is imperative to empower patients to take a more proactive approach to solving psychosocial discomforts using the everyday resources readily available to them. Where holistic assessments ask the patient to think about what they can do to address their own concerns, their checklist-and-signposting format offers no insight into how they might do this on a day-to-day basis.

Finding ways of assessing the assets that patients have, rather than what they do not have, may be a better starting point for psychosocial care. The findings of this study suggest that patients could be made aware of how other patients exercise self care using everyday resources. A vital key to this process is the meaning-making process demonstrated in the findings, which explores how participants assigned new values to familiar objects and experiences on a temporary basis in order to negotiate the curve thrown into life’s pathway by cancer. Two key activities emerge that could be helpful to people adapting to life after potentially curative treatment:

- Making patients aware of the everyday resources for recovery that they already possess by listing these resources based on four key categories that maintain a focus on each individual's social and material context:
social worlds, identities, places and spaces, and objects.
- Discussing how these resources might be harnessed to work towards the three key overarching aims common to all participants in this study:
control, comfort and continuity.

Social worlds: Considering the social worlds available to individual patients might be a more productive approach to assessing their social context than demographic characteristics. Adjustment to illness can be calibrated by reference points within these worlds: personal strengths can be drawn from family histories and inherited characteristics, and experiences of illness can be calibrated in comparison with those of other people. During the treatment phase, the clinic may provide a valuable temporary source of social capital. In the post-treatment phase, notions of community may be more relevant in deprived areas where people have lived in the same local area for many years; family support might also be significantly higher in such areas than in more affluent areas where the population is more mobile. Where contact in multiple social worlds is limited, adjustment can be more difficult – isolation from social interaction can be brought about by life circumstances additional to cancer: for example, the dynamics of additional illnesses in partners, in families, and within individuals in the form of comorbidities. These circumstances tangle the threads of the cancer experience, and may suggest the need to signpost or refer the patient to external agencies for help.

Identities: Every patient has a past, regardless of the quality of their social networks in the present: a focus on work and family histories can uncover psychological resources that some patients might not have considered. For those who have family, their role within the family can act as a placeholder for identities unconnected with cancer⁽¹³⁷⁾ and should be recognised. Patients may define their identity through differences from others, as well as through similarities. Taking a broader perspective, adaptation can be easier where families can be present, mark celebrations, make plans, and above all allow the person recovering from treatment to continue to fulfil tasks connected with

their pre-cancer roles and routines (for example, preparing food or walking the dog), despite a potential need for assistance where physical capabilities are lower.

Places and spaces: A consideration of favourite places inside and/or outside of the home, from armchairs to gardens to public spaces, can encourage their deliberate use for reducing anxiety. Favourite places were a key focus of participant photography in this research study, and participants described associated experiences of calmness or a sense of spirituality (regardless of religious beliefs). This allowed them to detach from or displace thoughts about illness and treatment. Places and spaces could be cues for feelings of familiarity and groundedness, as well as detachment and escape. A similar function was also served by local landmarks, the familiarity of which could be reassuring or symbolic of “home”. A minority of participants planned and took holidays in the year beyond treatment – some were looking for escape, others for familiarity where holidays had always been part of their life routine – but financial capacity for travel was not a prerequisite, as a similar function could be served by the home and local environment.

Objects: A consideration of how symptoms can be addressed using everyday objects can help to address changes in routine and recover independence by helping to facilitate the management of symptoms out of the house. For participants in this study, material objects took on new values during cancer treatment and recovery through being assigned new functions. For example, cooking timers transformed into a means of controlling nap times and fatigue; diaries were used to monitor the course of symptoms, appointments and small achievements; for prostate cancer participants, plastic urine bottles could allow travel while managing a frequent need to urinate. Sofas provided a less isolated place to rest than beds; books, television and radio took on fresh significance as new and unfamiliar stories displaced difficult thoughts. Other objects became imbued with new meaning or significance – for example, motivation and comfort was taken from gifts which were symbolic of love or care (and sometimes of practical use). The symbolism of objects was more readily felt as comforting than words in greetings cards, which could be interpreted in different ways dependent upon the mood in which they were received.

Control, comfort and continuity: Study participants directed their use of everyday resources in the home and local environment towards three key objectives: regaining control, creating comfort and chasing continuity. To regain control, they placed boundaries around unwanted symptoms (for example, avoiding the bedroom and timing naps to combat fatigue), or retained their independence by finding objects that helped them to accommodate symptoms outside of the house. Other objects were helpful psychologically rather than functionally, such as records of past and present achievements, and photographs of self and family which reinforced participants' personal characteristics and identities.

Comfort was achieved by placing a value on small acts of hedonism, by finding favourite spaces (indoors and out) to spend time in, by displacing difficult thoughts through creative tasks, and by investing in emotional connections with domestic pets. Chasing continuity involved actively working towards the re-establishment of familiar roles and routines (supported by family members), undertaking the effort required to maintain social and workplace connections, and by actively placing a value on mementoes and the memorialisation of past losses during treatment and recovery. The marking of celebratory events along the lifecourse such as christenings, birthdays or family gatherings reinforced social connections and provoked future orientation. Where participants had few or no family, or were less mobile, a sense of continuity within the wider world could also be achieved through staying in touch with national and global events which interested them via the internet or television.

11.4 Implications for future research

Social worlds theory is an appropriate approach for exploring categories of survivorship. Many more social worlds are implicated in the construction of "survivorship" than are described in the findings of this study. Future research expanding the use of situational analysis techniques to examine a range of stakeholder perspectives on this category of survivorship would begin to create a clearer picture of the survivorship arena. A focus on other timepoints beyond the first year after treatment, and on more complex experiences of cancer, would also

help to unravel the differences in patient experience (and professionals' perceptions of this experience) along this trajectory.

A focus on the creation of strategies for adaptation, rather than on examining distress and physical discomfort, would elucidate assets for recovery. Previous qualitative literature has been concerned to distinguish between positive and negative adjustment^(136, 149, 160) in a way that dovetails with the quantification of outcomes. Given the subtle differences in context between participants in this study, the role of social and material resources in adjustment, and the unhelpfulness of prescriptions for positivity, conceiving of adjustment along a continuum rather than as a dichotomy might help to facilitate a more personalised response to patients' circumstances.

Further investigation of the culture of radiotherapy units, as experienced by patients, could clarify how they might support a personalised approach to care and encourage peer support at the outset of treatment. Comparisons by cancer type would be imperative here, and lessons might be learned by investigating which features of clinic camaraderie (evidenced by prostate cancer participants in this study) might be transferable into other contexts. The experience of asymptomatic colorectal cancer patients also stands out as unique and in need of further research: where colorectal cancer is diagnosed through screening, patients can suffer an episodic lack of belief in their cancer. This discomfort can be compounded by unexpected humiliation on experiencing the mechanics of radiotherapy, and by uncertainties about what constitutes wellness in the months following surgery. Feelings of liminality can be more acute in colorectal cancer patients, and these concerns need to be addressed.

Given the agenda of individual agency in recommendations for recovery, with its focus on practices such as information-seeking and behaviour change, the evidence in this PhD study suggests that we need to develop a greater consideration of structural constraints and social mores in our analysis of patients' accounts of cancer. Concerns about anecdotalism in patient narratives⁽¹⁴³⁾ should not stop us from examining alternative routes or ranges of possibility for adaptation⁽¹⁶⁴⁾ based on individual experiences. As Aziz and Rowland⁽⁷²⁾ recommend, knowledge must be based on the viewpoints of the individuals we wish to help. We need to develop new vocabularies for survivorship. We can borrow concepts usefully from the sociology of chronic illness,

but it is time to explore recovery in its everyday context to develop a better sociology of living beyond cancer which accommodates a wider range of experience.

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Bold type denotes papers considered in Chapter 2: Literature review.

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Appendices

Appendix 1: Interview consent form

Setting Survivorship in Context: Life after cancer treatment

Interview Consent Form



Centre Number:
Patient Identification
Number:

Title of Project: Setting Survivorship in Context

Name of researcher: Alison Bravington

Please initial all boxes

1. I confirm that I have read and understood the information sheet dated 20.6.2013 (version 4) for the above study. I have been able to look at an information sheet about the study and ask questions, and have had any questions answered satisfactorily.	<input type="checkbox"/>
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my medical care or legal rights being affected.	<input type="checkbox"/>
3. I understand that this study is interested in my experiences of coping with life after cancer treatment, and will not in any way affect my medical care.	<input type="checkbox"/>
4. I understand that my participation will be kept confidential among those involved in recruiting for and carrying out the study.	<input type="checkbox"/>
5. I have been informed that the study will include two interviews, six months apart, and agree to take part. I give permission for the interview to be tape recorded, and understand that it will be typed up without using my name or any other identifying information.	<input type="checkbox"/>
6. I agree to the use of anonymised quotes from my interviews to be used in presentations and publications which tell other people about the results of the study.	<input type="checkbox"/>
7. I understand that I will be asked to take photographs before each interview, and that the photographs will be used in the interviews to help talk about my recent experiences.	<input type="checkbox"/>
8. I understand that I can take part in the interviews without taking photographs if I wish.	<input type="checkbox"/>
9. I understand that I will be given the opportunity to withdraw any photographs that I do not wish to be included in presentations or publications about the research project.	<input type="checkbox"/>

Name of participant Date Signature

Name of person taking consent Date Signature

SSC_Interview Consent Form v4_2.8.2013

Appendix 3: Participant information sheet



THE HULL YORK
MEDICAL SCHOOL

PATIENT INFORMATION SHEET

Setting survivorship in context:

Life after cancer treatment in an inner city

Researcher: Alison Bravington (PhD Student)

What is this leaflet about?

You are being invited to take part in a research study because we'd like to find out what life has is like for you now that you've had your cancer treatment. To help you decide if you want to take part, please have a look through this leaflet. Please talk to friends and family about it if you want to. This information sheet explains why the research is being run and why you've been asked if you want to take part. It explains what you would be asked to do. You can ask the research team to explain anything to you – please contact the research administrator, Helena Sinclair, tel: 01482 463128, e-mail: helena.sinclair@hyms.ac.uk. Helena will ask the researcher, Alison Bravington, to get in touch with you.

What is the study about?

When people finish cancer treatment, they don't have as much contact with doctors and nurses at the hospital as they did when they were being treated. We want to know what kind of support you might need while you recover from treatment at home, and we want to understand how living in an inner city area might affect the kind of help you need. We hope that this research will help us to provide the right kind of care in Hull and East Yorkshire, and in other inner city areas.

What would I have to do?

If you decide to take part, you will be asked to sign a consent form to give permission to interview you at home, or at a hospital clinic if you would prefer, at a time that's convenient to you. The researcher would interview you a few weeks after treatment comes to an end, and if you feel able to, will arrange a second interview six months later to see how things might have changed.

If you volunteer to take part in the study, you would be given a digital camera. About three weeks before each interview, you would be asked to take photographs of anything that might help us to understand what it's been like to cope after cancer treatment. The photographs don't have to be artistic, we just need quick snapshots of objects or places (or people, if you wish) to help us talk about your experiences in the interviews. You can keep the camera at the end of the project.

In the interviews, questions will be about what things in your life have changed because of your treatment, what it's like being at home and trying to get back to normal, and what kind of help you have or might need. We also want to know how the place where you live has affected your experiences. Each interview will take about an hour (this can be shorter or longer if you prefer). If you feel uncomfortable at any time you can stop taking part in the study, or not answer a question.

We won't be giving any feedback about your treatment to the people who have treated you – your interview will be completely confidential, and your name won't be used when we talk to people about the study. Taking part will not affect your medical treatment in any way.

Why have I been asked to take part?

You've been asked to take part because we want to speak to people who recently received treatment for your type of cancer.

Do I have to take part?

No. Taking part is your choice. If you decide not to take part this will not affect your medical treatment in any way. If you do take part you can withdraw at any time without giving a reason.

Expenses

You will be repaid any expenses when taking part in the study – for example, if you need to take a taxi to a clinic for an interview, we will pay for this for you.

What are the possible advantages and disadvantages of taking part?

It's unlikely that there will be any benefit for you in taking part. However, by doing so, you could help researchers to better understand the different problems faced by people in Hull and similar inner city areas after treatment for cancer. It is not thought that there are any disadvantages or risks from taking part, other than the time the study will take.

What happens after the interviews?

At the end of the study we will give you a summary of our findings if you wish. Any identifying information we collect will be kept strictly confidential, in accordance with the Data Protection Act, to protect your privacy. Real names will not be used when the interviews are typed-up, to make sure that you cannot be recognised from it. This is called anonymisation. The study results will be used to try new ways to reduce differences in patients' experiences of care after cancer treatment. We expect to publish the findings of this study in a research journal and present the findings at conferences. The findings will also be written up for the researcher's PhD.

SSC_Interview Study Participant Information Sheet v4_20.6.2013 Page 2

Who is organising the research?

The study has been organised and is being conducted by Hull York Medical School. The members of the research team are: Alison Bravington (PhD student), Professor Una Macleod and Professor Miriam Johnson. The University of Hull has funded the study. Approval has been given by the NHS Ethical committee and NHS Research and Development departments.

If I find it necessary to make a complaint, who should I contact?

Please raise any questions with Una Macleod (01482 463482, 8am to 5pm weekdays) or email una.macleod@hyms.ac.uk. If the research team can't give you a satisfactory answer, please contact Dr Barbara Hanratty (Senior Lecturer in Primary Care Research, Hull York Medical School, Department of Health Sciences, University of York) on 01904 321102 or e-mail barbara.hanratty@york.ac.uk.

Thank you for reading this information sheet. We are very grateful to you for thinking about taking part in this study.

Alison Bravington
PhD Student
Centre for Health and Population Sciences
Hull York Medical School, Hertford Building
University of Hull, Hull, HU6 7RX
E-mail: hyafb@hyms.ac.uk

Appendix 4: Photography brief

SETTING SURVIVORSHIP IN CONTEXT: LIFE AFTER CANCER TREATMENT



PHOTOGRAPHY INSTRUCTIONS

Thank you for agreeing to take part in this research. You've been given a camera to take some snapshots to help us talk about your experiences in the interviews. The next sheet explains what we would like you to take photographs of.

The photographs don't have to be artistic, they are just to help you to think about how things are for you at the moment, and to help the researcher to understand what might be important to you when we talk in an interview.

You can keep the camera at the end of the project. After the photographs have been taken, you will be able to decide whether you are happy for any of them to be used in research reports after the project. No-one outside of the research team will have access to the photographs at any time.

Please take one set of photos in the next week, then send your camera card back to the researcher in the stamped-addressed envelope supplied, or contact the researcher to pick the card up from you. The researcher will then arrange to interview you at a time convenient to you. About ten photos would be a useful number, but please feel free to take less or more than this.

SSC_Photography Instruction Sheet_v2_20.6.2013 Page 1

SETTING SURVIVORSHIP IN CONTEXT:
LIFE AFTER CANCER TREATMENT



Photography instructions

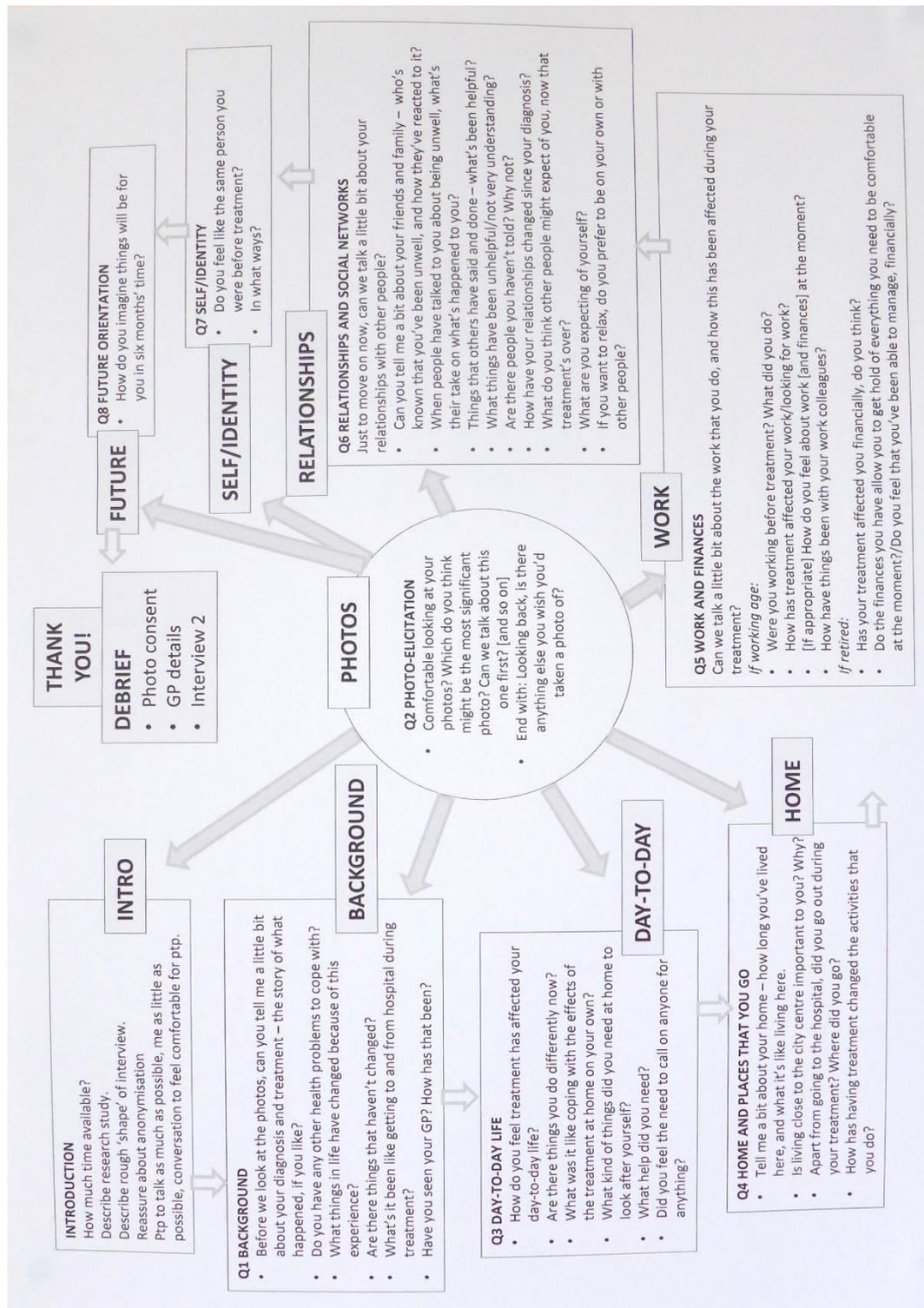
Please take photographs of anything to do with you, your home and your community or town that seem important to you at this time, for example:

- Things to do with coping with your treatment or its effects (anything you wish).
- Objects in your home or outside that are more meaningful to you now that you have been through diagnosis and treatment for cancer—any object, large or small. This can include day-to-day practical objects, or objects that are special to you because of your recent experiences.
- Everyday places or experiences that are important to you—please don't make a special trip for this, it can be snapshots inside your home, or places you go that are nearby.
- If you wish, do take photographs of people with their agreement, but be reassured that these will not be used in any reports from the research as we wish to respect people's privacy and keep their identity (and your identity) confidential.

About 10 photos would be a useful number, but please feel free to take less or more than this.

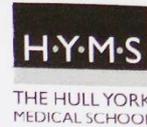
If you would like to talk to someone about taking the photos, please contact research administrator Helena Sinclair, tel: 01482 463128 , e-mail helena.sinclair@hyms.ac.uk. Helena will put you in touch with the researcher, Alison Bravington. Alternatively, please e-mail Alison at hyafb@hyms.ac.uk.

Appendix 5: Topic guide – First interviews



Appendix 6: Topic guide – Second interviews

SETTING SURVIVORSHIP IN CONTEXT: LIFE AFTER CANCER TREATMENT



INTERVIEW 2 TOPIC GUIDE

Q1 Catch-up/Day-to-day/Work (HOW ARE YOU, PHYSICAL SYMPTOMS, FOLLOW-UP, WORK AND LEISURE)

- How are you?
 - How have things changed for you, since I last saw you?
 - Have you had any follow-up appointments? Have you seen any one medical (inc GP)?
 - What about life is different, even just a little, because of the treatment?
 - What have your priorities been over the last six months?
- Are you back at work/do you use your time in the same way now as you did before treatment?

Q2 PHOTOS

Q3 Relationships (RELATIONSHIPS – CATCH UP, ONGOING SUPPORT, DO PEOPLE ASK?)

- How have other people been with you (and around you) over the past six months?
 - Have any relationships changed because of the cancer experience?
 - Does anyone refer to you being poorly/having treatment, now? (In good or bad ways?)
 - Thinking about the people who communicated with you when you were poorly, do they still communicate with you in the same way now?

Q4 Looking back

- How have you looked after yourself over the last six months?
- Where does the experience of the diagnosis sit in relation to the rest of your life, now?/How do you see that period of your life – the treatment and just after – now that you look back on it?
- Do you still think about it now? In what ways?
- Are there things that didn't change – that stayed the same?

Q5 Bigger issues

- Do you think the stories about cancer in the media are a fair reflection of the kind of experience you had?
- What advice would you give to someone going through the same thing, now?
- People sometimes talk in terms of cancer adding something to their life – does this make any sense to you? What's the whole experience been 'about', for you, if you can put it into words?
- We talked about the term 'survivor' last time we met, and I wondered whether you'd thought about it any further – what is a "survivor"?

Finish

- Is there anything you feel I should have asked you about, and haven't?

SSC_Interview 2 Topic Guide_28.5.2014

Appendix 7: Clinic Poster

Are you about to finish treatment for breast,
colorectal or prostate cancer after surgery,
radiotherapy or chemotherapy?

*Can you help us to provide a better service by
talking to one of our researchers about your
life after treatment?*



What would I have to do?

- Talk to a researcher about what life is like for you after your treatment.
- To help us talk, we'll give you a digital camera and ask you to take a few photos of everyday things in your life which mean something to you now that you've finished your treatment (e.g. things in your home or the places you go). **You can just talk to the researcher without taking photos if you prefer.**
- We'd like you to do the same thing again six months later.

Interested?

Please contact Alison (the researcher) by e-mail at hyafb@hyms.ac.uk, or Helena (research secretary) by telephone on 01482 463128.



Appendix 8: Ethical approval



Health Research Authority

NRES Committee London - City & East
Bristol Research Ethics Committee Centre
Whitefriars
Level 3, Block B
Lewins Mead
Bristol
BS1 2NT

Telephone: 01173421386
Facsimile: 01173420445

10 September 2013

Ms Alison Bravington
Hull York Medical School
Hertford Building, University of Hull, Cottingham Road
Hull
HU6 7RX

Dear Ms Bravington

Study title: Setting survivorship in context: Life after cancer treatment in an inner city
REC reference: 13/LO/1167
IRAS project ID: 129549

Thank you for your email of 09 September 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 24 July 2013

Documents received

The documents received were as follows:

Document	Version	Date
Other: E-mails received from University in response to request for evidence of insurance continuing for the duration of the study		09 August 2013
Participant Consent Form: Participant Consent Form - Interview	4	02 August 2013

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Interview Schedules/Topic Guides	3	20 June 2013
Investigator CV		
Other: CV: Chief Investigator		
Other: CV: Supervisor		
Other: Sponsorship: Hull York Medical School		
Other: Sponsorship: Uni of Hull Pro-Vice Chancellor Sponsorship		

Letter		
Other: Funding scholarship letter HYMS		
Other: Funding Additional Funding Letter		
Other: HYMS SEDA Lone Researcher Guidelines (May 2013)		
Other: Insurance 1: Insurance Uni of Hull		
Other: Insurance 2: Public Liability NHE 03CA04-0013		
Other: Insurance 3: Employers' Liability NHE 03CA04-0013		
Other: Photography Briefing Sheet (Interview Study)	2	12 July 2013
Other: E-mails received from University in response to request for evidence of insurance continuing for the duration of the study		09 August 2013
Participant Consent Form: Participant Photography	2	13 May 2013
Participant Consent Form: Participant Consent Form - Focus Group	2	20 June 2013
Participant Consent Form: Interview	3	20 June 2013
Participant Consent Form: Participant Consent Form - Interview	4	02 August 2013
Participant Consent Form: Participant Consent Form - Focus Group	2	20 June 2013
Participant Information Sheet: Focus group study	1	13 May 2013
Participant Information Sheet: Interview Study	4	20 June 2013
Protocol	8	20 June 2013
REC application		15 July 2013

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.

13/LO/1167

Please quote this number on all correspondence

Yours sincerely



Mr Rajat Khullar
Committee Co-ordinator

E-mail: nrescommittee.london-cityandeast@nhs.net

Copy to: *Professor Una Macleod,*
Mr James Illingworth, Hull and East Yorkshire Hospitals NHS Trust