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**Living with Cancer in Old Age: A Qualitative
Systematic Review and a Narrative Inquiry**

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**Submitted in fulfilment of the requirements for the
degree of PhD. Medical Sociology**

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Abstract

‘Living with Cancer in Old Age’ is an exploration of older people’s experiences of living with cancer, using qualitative research methods. A qualitative systematic review of international literature found that the experience of living with cancer in old age is characterised by ambiguity. There are sources of suffering, imposed by cancer itself, by treatments for cancer and by co-morbid disease. At the same time older people have access to sources of comfort and strength, both internal (attitudes of mental fortitude) and external (strong relationships with family, friends, communities and health professionals) which mitigate the worst effects of suffering. This literature study synthesised and interpreted findings from 11 studies covering a heterogeneous population of people aged 55-90+, representing a wide range of cancers at different stages of progress and treatment, across four countries (Israel, Canada, Sweden, USA) and using a range of qualitative methods.

A subsequent empirical study using narrative methods focused on a more homogenous population of older people aged 74-87, all resident in the same geographical region (NW England), with one of the four most common cancers (breast, colon, prostate and lung) at different stages of progress and treatment, but treated at the same cancer centre. In this study a biographical/narrative method of interviewing was used, in which 20 participants (13 men and 7 women) were invited to tell the ‘story’ of their life both before and after cancer. Interpretation of life history data reported by participants in this study suggests that the overriding features of life with cancer for people in their 70s and 80s are hope and hardiness, together forming a kind of resilience which appears to be psychologically protective and which fosters a determination to continue living positively, even at an advanced stage of illness. Whereas this ‘fourth age’ has been presented by sociologists as a life stage of inevitable decline, findings from the two studies conducted in this doctoral study indicate a quality of continuing robustness in the lives of some older people which runs counter to common assumptions about their vulnerability and frailty.

Contents

Introduction		Page 8
Part One	‘Experiencing Cancer’: A Qualitative Systematic Review	
Chapter 1	Search Strategy and Review Methods	Page 15
Chapter 2	Analysis and Interpretation of Findings	Page 49
Part Two	‘Cancer Stories’: A Narrative Inquiry	
Chapter 3	Research design, ethical considerations, sampling and recruitment	Page 68
Chapter 4	Data generation and analysis	Page 98
Chapter 5	Analysis and interpretation of findings (1): First signs or symptoms of cancer and medical Consultations	Page 120
Chapter 6	Analysis and interpretation of findings (2): Diagnosis and reaction	Page 143
Chapter 7	Analysis and interpretation of findings (3): Treatment	Page 156
Chapter 8	Analysis and interpretation of findings (4): Situating self in a life with cancer	Page 181
Chapter 9	Discussion and Conclusions	Page 203
	Reference List	Page 219

Appendix 1	Research Protocol	Page 239
Appendix 2	Participant Information Sheet: Long Version	Page 253
Appendix 3	Participant Information Sheet: Brief Version	Page 257
Appendix 4	Consent Form	Page 258
Appendix 5	Link to peer-reviewed publication: Hughes, N., S.J.Closs and D.Clark (2009). Experiencing Cancer in Old Age: A Qualitative Systematic Review. <i>Qualitative Health Research</i> , 19 (8): 1139-1153. http://qhr.sagepub.com/content/19/8/1139	Page 260

List of Tables and Boxes

Table 1.1	Provisional bibliographic sample and location source
Table 1.2	Summary of analytic techniques applied to extracted findings from research reports
Table 1.3	Initial Appraisal Template/Reading Guide
Table 1.4	Summary data from provisional bibliographic sample
Table 1.5	Cross Comparison of Study Reports by Topic
Table 3.1	Cancer Stories: Demographic characteristics
Table 3.2	Cancer Stories: Disease Characteristics
Table 5.1	First Symptoms and Medical Consultation
Table 7.1	Treatments experienced by each participant
Box 1.3	Example of search including ‘filter’ for qualitative research
Box 1.4	Journals searched manually
Box 1.5	Decision Rules for Extracting Findings from Qualitative Research Reports for an Integration Study
Box 4.1	The developing ‘SQUIN’
Box 4.2	Extracts from field texts regarding chosen method of narrative interviewing
Box 8.1	Defining attributes of resilience
Box 9.1	Extracts from Reflective Research Journal considering the challenge of linking two different studies

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I wish to record very special thanks to all the men and women who agreed to participate in my empirical research and to tell me their 'cancer stories'. I dedicate this work to them and to their families, to my own extended family and, more particularly, to my wife Kate Fleming and our children, Róisín Hughes and Séan Hughes.

Author's Declaration

I declare that, except where explicit reference is made to the contribution of others, this thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Signature:

Printed name: Nicolas David Hughes

INTRODUCTION

This thesis reports the methods and findings of a research inquiry which investigated older people's experiences of living with cancer. In this Introduction I set out the background to two studies which I conducted to answer the overarching research question: 'What are the subjective experiences of older people of living with cancer?' I explain the research problem and the aim of my studies and indicate the research questions which guided my inquiry. I make some observations on the nature of cancer in older age and on specific features of ageing in modern society. I close the Introduction with a chapter-by-chapter summary of the structure and contents of the thesis.

Research Problem

Despite increasing longevity and generally improving health in Western populations the process of ageing is associated with greater incidence of disease and illness, in particular of degenerative conditions such as musculo-skeletal disorders, ischaemic heart disease, neurological impairments and cancers. Comorbidity is common in individuals aged 70 and older (Stevenson et al 2004; Extermann 2000) and cancer has its highest incidence in older populations. There is extensive literature reporting the incidence and prevalence of cancers in older age groups along with approaches to treatment and the effects and management of comorbidity (Bennahum et al 1997, Extermann et al 1998, Satariano & Silliman 2003). However, the subjective perceptions of older individuals undergoing the experience of cancer remain largely unknown.

Aim of the research

Approximately half of all cancers diagnosed in the United Kingdom are in people aged 70 or older (NCIN, 2008). The aim of my research inquiry was to investigate the experiences of older people of living with cancer. My specific focus of interest was the experience of people aged 75 and older, since this appears to be a hidden population whose experiences are largely unknown. Individuals

aged 75 and older are rarely represented in cancer research or policy documents. In the qualitative systematic review which I conducted (described in detail in chapters 1 and 2 of the thesis), for example, only two of eleven studies selected for review (from an international sample of 262 papers) were of patients aged 75 and older and, in the United Kingdom, Department of Health cancer publications since 2000 focus predominantly on the under 75s (DoH, 2000; 2005; 2007).

The Public Service Agreement target for cancer mortality for the period 2008-2011 focuses on reducing deaths in people under 75 years by 20% (Wilkins et al 2008) and, indeed, the overall mortality rate from cancer in people under 75 continues to fall (Allberry, 2008; NCIN, 2008). There is no mention of a target in the Public Service Agreement to reduce mortality in those older than 75. Little progress has been made in improving mortality among people in that age group and the gap in death rates with other countries is getting wider (NCIN, 2008). The picture of older people, especially women, experiencing higher relative risk of dying from their cancer than younger people, is replicated across Europe, but not in the USA (O'Connor, 2010).

Cancer may behave differently in those over 75 (Thomé et al 2003) and its progress may be influenced by the presence of coexisting diseases of old age (comorbidity) (Bennahum et al; 1997; Extermann et al 1998; Satariano & Silliman, 2003). Although there is extensive literature reporting clinical and epidemiological research into older people and cancer, little is known about the experience of having cancer in older populations from the individual's point of view. There is continuing concern though, that older people's specific needs, both physical and psycho-social, are not sufficiently considered, independently of their chronological age, when prescribing treatment and care for cancer (Bailey et al 2003; Kagan, 2008; Porock et al 2009).

Research Questions

The fundamental purpose of this research is to gain knowledge of, and to understand, the impact of cancer on the lives of older people. What happens

when an older person develops symptoms and signs of cancer? What is it like to receive a diagnosis of cancer and to go through what can be complicated treatments which older people often find it difficult to tolerate (Pergolizzi et al 2001). Having completed active treatment for cancer, what is the experience of everyday life living with the after effects of the cancer? What if treatment is not indicated? What is the effect of all this on living with other chronic diseases or long-term conditions concurrently with the cancer? Answers to such questions have rarely been sought from older people themselves.

The research questions which guided this study are:

- What is the impact of a cancer diagnosis on older people?
- How are decisions about treatment made?
- What is the impact of cancer treatment on the life of the older person?
- What is the impact of cancer on the person's daily life?

Study Methods in Outline

In the framework outlined by Robson (2002)) the purpose of this research is predominantly *exploratory* rather than *descriptive* or *explanatory*. Important aspects of exploratory enquiry are that it seeks to find out what is happening, particularly in little understood situations; to seek new insights; to ask questions and to assess phenomena in a new light.

I conducted a **qualitative systematic review**, therefore, of older people's experiences of living with cancer in order to investigate the gap in the literature and to produce new knowledge concerning older people's experiences of living with cancer (Hughes et al 2009, included at Appendix 5, p.260). This qualitative systematic review will be referred to here as *Experiencing Cancer* and is reported in Chapters 1 and 2 of the thesis. I followed this systematic review with an **empirical study, using narrative methods**, of a population of people aged 75 and older and living with cancer in the North West of England. This study will be referred to as *Cancer Stories* and is reported in Chapters 3-8.

Some Observations on Defining Old Age

Ways of categorising and defining older people vary and shift over time, across gender and across social class. For most of the twentieth century old age has been defined in relation to work and to chronology; specifically, in relation to the age at which retirement from paid work may cease and eligibility for a pension begins. The 1908 Pensions Act set the (non-contributory) state pension age at 70 and represented the first time connections were drawn between chronological age and pensions, though it did not necessarily signify retirement in the sense of an end to paid work.

The retirement age was reduced from 70 to 65 under the provisions of the 1925 Old Age and Widows and Orphans Contributory Pensions Act, for those people making contributions under the 1911 National Insurance Act. Predicated on the 'male breadwinner' model, the overwhelming majority of married women were only included in a subordinate and conditional sense as 'wives' or 'widows'. Social class differences were also seen in that the occupational pensions enjoyed by the civil service since the mid-1850s were available from the age of 60 (Thane, 2000). Though this was not formally implemented as a pension policy, most civil servants did retire in their mid-sixties, on the basis of being too old to work, whereas manual workers and women were not officially defined as old until they reached the age of 70 and qualified for a pension under the 1908 Pensions Act.¹

At the time of writing the 'official' retirement age, the age at which a person becomes eligible to receive the state pension, and the assumed start of old age, is 65 for men and 60 for women, though it is set to be equalised at 65 years between 2010-2020 and to rise to age 68 by 2044 (DWP, 2006, p.19). On the other hand, charities providing advocacy and services for older people (eg Age Concern) include people over 50 in their target population, as does a well-known insurance provider (Saga) and a voluntary education provider (University of the Third Age or U3A). 'Early retirement,' is sometimes offered from the age of 50 under the terms of contributory occupational pension schemes.

¹ <http://openlearn.open.ac.uk/mod/resource/view.php?id=285234> accessed Sept 2nd 2009

Increasing Longevity

The National Service Framework for Older People (DOH, 2001) reports a doubling of the population aged over 65 since the early 1930s to a position where a fifth of the population is over 60. This ageing population is set to rise so that between 1995 and 2025 the number of people aged over 80 will increase by almost a half and the number of people over 90 will double.

As long ago as the 1970s American social researchers responded to the increase in the older population by describing those between 65 and 75 as the 'young-old' (Neugarten, 1974;1975) with the implication that those over 75 are the 'old-old.' It seems more common now to refer to those over 80 as the old-old. The number of centenarians also continues to rise (9300 in England and Wales in 2007 compared with 100 in 1911²) and, worldwide, there is a tiny group of individuals living beyond 110 known as 'supercentenarians' (Rutherford, 2009). So, although there are some overlapping definitions, those aged 75 and older may be regarded as among the 'old-old' or, as some describe it (Asquith, 2009; Bhatti, 2006; Vincent, 1999) as having entered the 'fourth age.'³ Vincent (1999) and Asquith (2009) both present the fourth age as a period of inevitable decline and it was an assumption that this population is subject to a double jeopardy-of frailty and invisibility- which prompted my interest in this research topic.

Structure and Contents of the Thesis

Chapters 1 and 2 report the methods and findings of a literature review, formed from a substantial synthesis of qualitative studies which investigate older people's experiences of living with cancer. This literature review represents a qualitative study in its own right, which has been published in a peer-reviewed journal (Hughes et al, 2009, included at Appendix 5). In this thesis it is referred

² <http://www.statistics.gov.uk/pfdir/eldpep0908.pdf> accessed Sept 2nd 2009

³ Vincent argues that the fourth age is a social construct in which expectations of continuing health are low, corresponding to the rising expectations of health among those in the 'third age' p 142. Asquith (2009) assumes that the fourth age is a time of mental and physical decline (p267).

to, for convenience and to distinguish it from the empirical narrative study which is also reported here, as *Experiencing Cancer*.

In **Chapter 3**, I describe and justify the research design of an empirical study, given the brief title *Cancer Stories*, and present the approach taken to ethical considerations. I detail the sampling and recruitment procedures and present brief biographies of the study participants.

In **Chapter 4**, I report and reflect on the methods chosen to generate, analyse and interpret the narrative data generated in *Cancer Stories*. I begin with some commentary on epistemological matters concerning qualitative research data before going on to a detailed account of the primary method of data generation used in the study, the Biographic-Narrative-Interpretive Method or 'BNIM' (Wengraf, 2008, 2001). I go on to describe and explain at length the methods used to transcribe the interview data and subject them to a two-stage narrative analysis based on the concept of the *illness trajectory* (Corbin & Strauss, 1988) and on a reading of participants' illness narratives ('cancer stories') in the light of their life histories.

In **Chapters 5-7**, I report in detail findings from the narrative study which relate to the pre-diagnostic, diagnostic and treatment periods of the participants' experiences of cancer. I present the findings with interpretive commentary in the light of relevant literature. I begin with analysis of the participants' stories of the first signs or symptoms of cancer and their help-seeking behaviour (Chapter 5). I go on to report their experiences of receiving and reacting to the diagnosis of cancer (Chapter 6) and conclude by reporting their experiences of treatment (Chapter 7).

In **Chapter 8**, based on close analysis of the life history elements of the interview transcripts, I interpret the 'cancer stories' to suggest that the overriding features of situating self in life with cancer among the participants in this study are hope and hardiness, together forming a kind of resilience which appears to be psychologically protective and which fosters a determination to continue living positively. I go on to consider the data in the light of analytic

questions which help to situate the private individual experiences of the participants in a wider social context.

In **Chapter 9**, I conclude by attempting to draw out the significance of findings from both studies, systematic literature review and empirical investigation, for our understanding of older people's experiences of living with cancer. I review and reflect on the identification of a research problem, the formulation of a research question and the principal approaches adopted by way of investigation. I consider the strengths and limitations of the chosen methods (qualitative systematic review and narrative inquiry) and discuss the challenges of comparing findings from two studies which attempt to answer the same question but which use different methods. I summarise the key findings across both studies and conclude the chapter, and the thesis, with some observations on the transferability of the findings to wider populations.

CHAPTER 1

‘EXPERIENCING CANCER’: SEARCH STRATEGY AND REVIEW METHODS

1.1 INTRODUCTION

I designed and conducted a systematic search and review of qualitative research literature which investigated older people’s experiences of living with cancer (Hughes et al, 2009). Reports of research studies traditionally begin with a review of existing literature in the field. A literature review sets the context for a research study, revealing gaps in existing knowledge which the study intends to fill. Scholarly expectations in the field of healthcare research about the rigour with which such a review is conducted have been rising in the last decade. Researchers are expected to replicate the research process itself in respect of the literature search; that is, to develop a search question and a search strategy which includes methods of searching, retrieval and analysis of the sample of literature retrieved. The result of this analysis should be a critical review, not just a descriptive or narrative summary, which provides appraisal of the quality of existing work.

To make the most effective use of research findings, approaches to synthesising the results of many studies on the same topic have increasingly found favour and, in quantitative research, sophisticated methods of meta-analysis have been developed which aim to produce a definitive set of findings from a wide range of work. In qualitative research such an approach is deemed to be an essential part of increasing the usefulness and relevance of findings (Sandelowski et al 1997) though the methodology is at an earlier stage of development (Dixon-Woods et al 2007; Popay and Roën, 2003) and there has been debate about whether the approach is epistemologically appropriate for qualitative research (Campbell et al 2003; McDermott et al 2004; Sandelowski et al 1997). This approach is termed variously ‘metastudy’, ‘metasynthesis’, or ‘research integration’. It is an approach to the literature which is more than a critical review, but an attempt to integrate findings across studies in order to arrive at new understandings.

My reading of methodological literature in the field of qualitative reviewing and synthesis (Barbour, 2001; Booth, 2001; Britten et al 2002; Campbell et al 2003; Noblit and Hare 1988; Paterson et al 2001; Sandelowski & Barroso, 2006) led me to conceptualise the review of the literature reported here as a ‘qualitative systematic review.’ This seemed to me the most accurate rendering of a pragmatic combination of methods and concepts to be found in a field still under development and with ever-changing, and sometimes conflicting, terminology. There is continuing methodological debate about what exactly constitutes a synthesis, for example. My purpose was not specifically to develop the methodology of qualitative meta-synthesis, or rigidly to apply one set of techniques. Rather, I took a flexible and eclectic course (Johnson et al 2001), applying methods from different sources to examine in detail the findings of qualitative research which reports older people’s experiences of living with cancer.

In this chapter I present the methods used to search and review relevant primary research. I present analysis and interpretations of the review findings in the next chapter.

1.2.1 Systematic Literature Search

The question that guided a search for relevant studies was, “What qualitative research literature is available which reports experiences of living with cancer of adults aged 75 and over?” Studies were identified through searching electronic databases, manual searching of purposively sampled journals, follow-up of references and consultation with authors and experts. Studies were retrieved if they were reports of primary qualitative research, focused on older people with cancer and written in English.

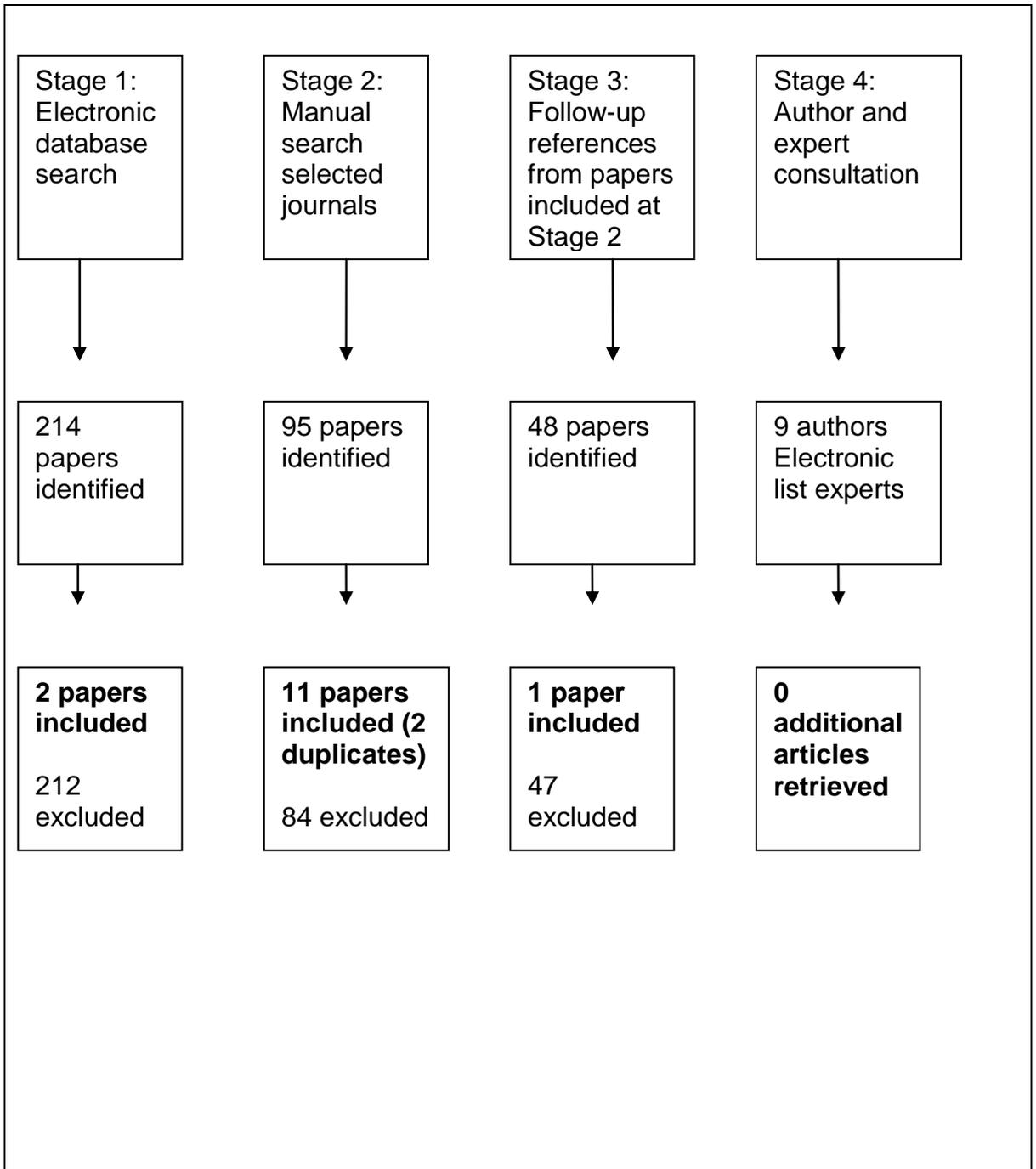
The purpose and methods for study identification and retrieval for metastudy are contested in the methodological literature. One approach is to identify and retrieve all studies relevant to the search question. But there is debate over the extent to which a search needs to be *comprehensive* (covering all possible

sources of material) and/or *exhaustive* (retrieving all material that is relevant to the research question). Most authors agree that both are necessary but there are dissenting voices (Barbour 2001; Booth 2001) arguing that methods could appropriately be modelled on sampling for primary qualitative studies. For example, purposive or theoretical sampling and the concept of 'data saturation' could legitimately be applied to samples of papers. From this perspective, the intention is not to identify all literature on a particular topic; rather, it is to identify specific groups of papers with characteristics relevant to the phenomenon being studied (Booth 2001). This was the approach taken in this study. The goal was explicitness of methods rather than completeness of sampling (Edwards et al 2000, 1998).

A four stage process of literature searching was undertaken comprising i) electronic searches of bibliographic databases (section 1.2.2); ii) manual searching of purposively selected journals (section 1.2.3); follow-up of reference lists (section 1.2.4); and, author and expert consultation (section 1.2.5). A summary of each stage can be seen in Box 1.1, p.18).

At each stage of searching abstracts were retrieved if the title included reference to cancer and to older adults (explicitly or implicitly) but were excluded if it was clear from the title that the paper was about cancer-related health promotion or screening. Titles were also excluded if they were clearly not full reports of primary research: for example; conference abstracts, editorials/commentaries or news reports. If it was not clear from the title or the abstract that the study reported primary qualitative research about older people and cancer then the paper was retrieved and read against the inclusion criteria. Papers were included in the provisional bibliographic sample if they reported qualitative studies of older adults which investigated accounts of individuals' experiences of living with cancer.

Box 1.1 Summary of four-stage literature search



1.2.2 Stage 1: Searches of electronic bibliographic databases

Subject and key word searches were conducted of seven electronic databases (Box 1.2 p.19) using a range of terms representing *old age*, *cancer*, *experience*,

chronic illness. An early ‘scoping search’ using the keywords ‘living adj2 cancer’ combined with ‘age\$ or elder\$ or older\$’ yielded two reports, from 156 records returned, of a qualitative study exploring the experience and meaning of living with cancer in old age (Thomé et al 2004; 2003). These reports met the inclusion criteria and were included in the provisional sample.

Box 1.2 Electronic Databases searched (all via OVID)

AMED (Allied and Complementary Medicine) 1985-2006
British Nursing Index 1985-2006
CINAHL 1982-2006
Embase 1980- 2006
International Bibliography of the Social Sciences 1951-2006
Medline 1966-2006
PsycINFO 1985-2006

Subsequent searches were more detailed, including subject headings and a qualitative ‘filter’ (Wilczynski et al 2007) designed to maximise the retrieval of qualitative studies. This search strategy can be seen in Box 1.3 (p.33). The search was conducted in October 2006 and yielded 214 records. One hundred and sixty four titles referred to aspects of chronic illness unrelated to older people, thirty nine titles referred to older people, eight titles referred to people with cancer, and just three titles referred to older people with cancer. Abstracts were obtained for these three articles. Hughes et al (2000) was a study of advanced nurses’ teaching interventions rather than of patient experiences. Zanchetta (2002) was a study of healthy older men’s handling of health information related to prostate cancer, not a study of older men with prostate cancer. Neither of these papers met the inclusion criteria and both were excluded from the review sample. The third abstract retrieved (Overcash 2001) was from a doctoral thesis reporting a narrative study designed to understand the effects of breast cancer on the lives of older women. This study met the inclusion criteria but the thesis was not retrieved on the grounds of time and cost required to access, read and analyse a thesis. An article based on this

research (Overcash, 2004) was identified in the manual search (see section 1.2.3 below) and was included in the review sample. Overall, electronic searches were unsuccessful in identifying relevant studies.

1.2.3 Stage 2: Manual searching purposively sampled journals

In this phase the intention was to widen the field of search beyond electronic bibliographic databases in the hope of locating relevant qualitative studies. A scoping search was conducted for potentially relevant journals accessible through the University of Leeds library catalogue. I looked for journals concerned with cancer or ageing, and for journals concerned with social science or qualitative research. I excluded journals concerned with palliative or end of life care as the focus of the review is on living with cancer rather than dying from the disease. Seventeen journals were located and the contents lists searched covering a period of ten years 1996-2006, where available (see Box 1.4 p.35). Thirteen journals located in the catalogue were accessible electronically and contents lists were searched on-line. Four journals were accessible in print versions only. Library visits were required to scrutinise contents lists for these journals and to photocopy potentially relevant abstracts and articles. Relevant print articles were subsequently scanned into electronic format.

Articles were screened by title (contain reference to cancer AND older people) and then by abstract (contains clear reference to the study being concerned with some aspect of older people's experiences of living with cancer; clear indication of qualitative methods; written in English). Ninety five titles in fourteen of the selected journals contained reference to older people and cancer. Abstracts were sought if the title included reference to cancer and to older adults (explicitly or implicitly) but the articles were excluded if it was clear from the title that the paper was about health promotion or screening or if there were clear indications that the article was not a full report of primary research; for example, conference abstracts or editorials/commentaries. Twenty citations were excluded on the basis of title screening. From the remaining 75 citations a further 55 were excluded after reviewing the abstract (50 were reports of studies using quantitative methods, four were not research

reports and one was a survey of a population of older people without cancer). The full report was retrieved if a) the abstract contained clear reference to the paper being a report of primary qualitative research investigating older people and cancer or b) the report was a mixed methods study investigating older people and cancer which the abstract suggested contained a qualitative component; or c) if it was not clear from the abstract whether the paper was i) a research study or ii) a qualitative research study. Twenty reports were retrieved. Eleven met the inclusion criteria and were included in the review sample. Two of the papers retrieved by manual searching were also located in the electronic search (Thomé et al 2004; Thomé et al 2003).

A provisional bibliographic sample of 11 qualitative research reports was obtained by the combination of electronic and manual searching. Only two of the studies retrieved focused exclusively on people aged 75 or over (Thomé, Esbensen et al 2004; Thomé, Dykes et al 2003). These were different interview-based studies by the same research group. One study investigated the experiences of 41 older people living with cancer, focusing on a sub-sample of a large population study, using content analysis (Thomé et al. 2003). The second study was a phenomenological investigation, specifically focused on the perceived meaning of living with cancer in old age, using a purposive sample of 10 individuals over 75 (Thomé et al. 2004).

Because so few studies concentrated on the target age group for this review, I decided at this stage to accept authors' implicit definitions of older people (the age range of participants in the provisional bibliographic sample was 51-99) and to make this qualitative systematic review a study of older people living with cancer.

1.2.4 Stage 3: Follow-up of references

Reference lists of the eleven papers included in the sample from electronic and manual searches were also scrutinised for titles which met the screening criteria of containing reference to older people and cancer. Forty eight citations were identified in this way. Thirty one citations were inaccessible (not in library

catalogue; print versions only available; reference details incomplete or inaccurate). Sixteen citations were excluded after reviewing the abstract because they were reports of quantitative studies or were not research publications. One study (Adler et al 1998) met the inclusion criteria and was included in the (still provisional) bibliographic sample.

1.2.5 Stage 4: Author and expert consultation

Brief details of the research were emailed to authors of the included studies and to an expert panel, along with the search strategy and results, with a request for suggestions as to additional electronic databases or journals which may be searched or any relevant articles personally known to them. Nine authors were contacted by personally addressed email. There were no contact details for one author; a second had been excluded after the review process; two studies in the bibliographic sample were by the same first author. The expert panel was contacted by addressing an electronic list comprising self-selected members of the Cancer Experiences Collaborative Older Adults theme. Email addresses were not recognised for three authors. Replies were received from one author and from five members of the expert panel. Suggestions included: contact other researchers known to be working in the field (names given); two additional electronic databases with facility for citation tracking; two citations and abstracts. No additional articles were retrieved which met the inclusion criteria as a result of following up these suggestions.

1.2.6 Evaluation and reflection on search strategy and methods

Initial literature searches using electronic databases were rudimentary as I began to retrieve skills unused for some time and to develop new competence in searching systematically. Studies retrieved during early searches were all clinically orientated (diagnosis, treatment) quantitative studies or were epidemiological studies concerned with matters of incidence, prevalence, public health. None of these studies were about patients' experiences. Recognition that the patient perspective, the main focus of my planned empirical study, was absent from these studies propelled my searches in a different direction.

Discussion with a healthcare librarian and reading more widely (Barroso et al 2003, Paterson et al 2001, Wilczynski et al 2007; Wong, 2006) revealed that indexing of qualitative studies in electronic bibliographic databases is limited and varies between databases, making identification of qualitative studies difficult. This was confirmed at a later stage when author searches of papers included in my final sample yielded all but one of the reports I had located by manual searching but which had not been identified during electronic searches. Running electronic searches using a qualitative 'filter' designed to maximise the yield of qualitative studies (Wilczynski et al., 2007) did not prove fruitful however.

Searching was iterative and reflective, informed by the metaphor of 'berry picking' (Barroso et a., 2003). While seeking to be systematic and rigorous in applying standard techniques (ie electronic searching) experience showed that a linear, sequential method, however systematic, was insufficient to locate qualitative studies.

At each stage of the search, the searcher is not just modifying search terms to get a better match for a single query. The query itself is continually shifting, in part or whole. This is called an evolving search and is closer to the actual behaviour of searchers. The query is satisfied not by a single final retrieved set but by a series of selections of individual references and bits of information at each stage of the ever changing search. This is not a straight, linear process. Just as a berry picker would meander through the bushes looking for clumps of berries the searcher wanders through the information forest, changing directions as needed to follow up on various leads and shifts in thinking (Barroso et al 2003: 159).

Barroso et al's metaphor of berry picking guided not only the search but the decision to stop (or postpone) searching. My aspiration throughout this phase of searching was to locate and retrieve a collection of relevant qualitative research reports that would be deemed sufficient in number to conduct a meta-synthesis. Deriving from the meta-ethnographic method pioneered by Noblit & Hare (1988) meta-syntheses typically include relatively small numbers of studies. Noblit & Hare, working in the field of education research, recommended the approach

with between four and six studies which used similar methods to each other. Researchers who developed the method in health and social sciences argued that meta-methods could be used successfully with studies which used a range of different methods (Campbell et al 2003). Campbell et al's sample was four studies, though their study was specifically to test the methodology across different study designs. Meta-syntheses in teenage motherhood (McDermott et al 2004) and in chronic leg ulceration (Briggs & Fleming 2007) included fewer than 20 studies. Research teams working in the fields of motherhood and HIV (Sandelowski and Barroso 2006) and chronic illness (Paterson et al 2001) conducted meta-syntheses of larger numbers of studies (56 and 246 respectively). Paterson et al recommend a minimum of 12 studies for a meaningful meta-synthesis. With 12 relevant studies retrieved, and limited time for additional searches, I decided to begin review of the reports and to postpone further searching.

Literature searching for this review was conducted systematically and with an attempt to be comprehensive, using a variety of methods. Ultimately, a purposive sample of reports was obtained which represented a useful and workable sample for meta-study or, in what became my preferred phrase, *qualitative systematic review*. Experienced meta-study researchers note that even the most rigorous search will miss some relevant articles (Paterson et al 2001). It should also be noted that while the search process was rigorous and methodical, it was not tidy. The account given here does not reveal the false-trails, the frustrations, the subtle shifts in thinking, or the surprises, satisfactions and rewards, which characterised the whole experience.

The provisional bibliographic sample can be seen in Table 1.1 (p.36). It is described as provisional because the analytic process I used (Sandelowski & Barroso, 2006) allows for later exclusions (see Locating and Extracting Findings below, p.27). Of the twelve studies included at this stage three were studies of men with prostate cancer (Harden et al 2006, Hedestig et al 2003, Navon & Morag 2004) and four were studies of women with breast cancer (Adler et al 1998, Feher & Maly 1999, Overcash 2004, Roberts et al 2006). One study investigated the experience of older women with a range of gynaecological

cancers (Sinding et al 2005) and the remaining four papers reported studies of men and women with a range of cancers (Duggleby 2000, Ryan 2005, Thomé et al., 2004, 2003). The studies were conducted in Canada (2), Israel (1), Sweden (3) and the USA (6). The total number of informants across all studies was 215 , the sample range was 5-41 and the age range of participants was 51-99.

1.3 Evaluating papers and extracting findings

The aspiration for this review was to produce a meta-synthesis of qualitative research which reported older people's experiences of living with cancer. A range of articles and books on meta-methods inspired this approach to the qualitative literature review (Britten et al 2002; Campbell et al 2003; McDermott et al 2004; Paterson et al 2001; Sandelowski et al 2007, 2003a, 1997) and it was from among this group of authors that a framework was chosen for review and analysis of the sample of reports selected for this qualitative systematic review. Sandelowski and colleagues produced a series of papers from the late 1990s onwards documenting and reporting on their attempts to develop the methodology of qualitative meta-synthesis or, as they came to call it, 'research integration studies'. Coincidentally for the timing of my study their project culminated in the publication of a handbook which became a source to guide my approach (Sandelowski & Barroso, 2006). While this has proved a useful framework for my analysis I have found it necessary to adapt the method and to introduce analytical techniques from other sources. Table 1.2 (p.38) summarises the analytic method used in this review, comprising the application of six key stages in Sandelowski & Barroso's framework, with the addition of a method for presenting the summarised findings derived from Noyes and Popay (2006) and a working hypothesis derived from the findings.

1.3.1 Initial study appraisal

Close reading is at the heart of any process for review and analysis of research reports, particularly in qualitative studies which are conducted predominantly in the medium of language. In Sandelowski and Barroso's framework, familiarity with the contents of each report in the bibliographic sample is fostered by a

systematic analysis (literally ‘taking apart’) of the report using a reading guide (Table 1.3 p.39) which mirrors the structure of a research report. Table 1.4 (p. 40) presents a summary of data from the provisional bibliographic sample, derived from the initial appraisal.

A number of important observations may be made about this process. First, the phrase ‘initial appraisal’ has particular significance because, while it signifies the making of judgements about the ‘quality’ of the report it does not use these judgements as a basis for final decisions about whether to include the report in the study. A number of authors (Campbell et al 2003, McDermott et al 2004, Paterson et al 2001) do use quality appraisal in this way to determine a sample of studies for meta-synthesis, and a general case has been made for the importance of appraising qualitative research systematically (Long & Godfrey, 2004). Sandelowksi & Barroso argue, however, that this is not a good basis on which to make inclusion decisions, mainly because there is still (surprisingly) little consensus on quality indicators for qualitative research (Dixon Woods et al., 2007). The appraisal that is made is, therefore, a provisional one and is based on the concept of the amount of ‘signal’ in the report versus the amount of ‘noise’ (Edwards et al 2000, 1998). ‘Signal’ refers to the clarity and relevance of the findings, ‘noise’ refers to possible methodological flaws or reporting limitations which might obscure such clarity or make the credibility of the report questionable in some respects. Sandelowski & Barroso argue that it is the quality (or credibility) of the *findings* which should be appraised following a detailed process of review and analysis.

The only reasons for excluding a report from a meta-study, within the parameters of this framework, are that a study appears to have been conducted unethically or that on close reading and examination the report is discovered to contain no findings (Sandelowski & Barroso, 2006, 2003b). In this qualitative systematic review, all original studies included in the review contained evidence of having been conducted according to ethical principles, and received ethical approval from an appropriate institution. One study (Ryan 2005) was eventually excluded on the grounds that it was difficult to discern findings as defined in the review protocol (see Locating and Extracting Findings p.27, below). Perceived

methodological limitations, for example, the lack of a substantive or formal theory in a grounded theory study, were not deemed in themselves to invalidate a study's findings and were not used as a basis for exclusion.

A second important dimension of this initial appraisal is that, even for an experienced reader of qualitative research reports, the process of identifying findings can be surprisingly difficult. This is described more fully in the next section *Locating and Extracting Findings*.

A third observation is that although this process is time-consuming it is an invaluable way of becoming familiar with the studies. Sandelowski & Barroso recommend paraphrase or verbatim transcription of the material contained in the report. In general I found the verbatim transcription to be a more reliable way both of fostering such familiarity and of ensuring fidelity to the original report during the later stages of working with the findings.

1.3.2 Locating and extracting findings from included papers

Findings, or results, from qualitative research reports form the raw data for a qualitative research integration project. It is important therefore to identify and locate all statements in a report which constitute the findings from the research. Findings were defined in this project, following Sandelowski & Barroso (2002 p.214), as 'the data-driven and integrated discoveries, judgements or pronouncements which researchers offer about the phenomena, events, or cases under investigation'. The following types of statement which appear in research reports are not findings within this definition and were not extracted (see Box 1.5 pp.44-7 for detailed explanation of the rationale for these decisions):

- direct quotations from interview data offered in support of findings
- statements which indicate that they are portions of interview data, even though they are not direct quotations
- statements which offer the authors' views on the clinical, educational or research implications of the results
- statements which refer to findings from other studies or from academic literature.

The structure and style of qualitative research reports are not standardised and frequently adopt a format which Sandelowski & Barroso (2006) call ‘amended experimental report’. This is a reference to the standardised format for reporting in scientific studies, which is often modified in qualitative research reports. The effect of such modifications, and its significance for a research integration project, is that findings, or results, may be reported in sections of a report other than those headed ‘Findings’ or ‘Results’. Reports must be read closely and thoroughly, therefore, with the working definition of a finding held in mind, in order to be sure of locating all the findings reported.

The process for extracting findings was guided in this project in two ways. First, a process of ‘initial appraisal’ was undertaken whereby each report was read in detail and re-structured according to a detailed framework. This process gave an initial sense of what material in the report could be said to constitute its findings. Second, following Sandelowski & Barroso’s (2006) recommendation, a set of decision rules was written, based on the definition of a finding stated above, to guide the extraction of findings more clearly. Decision rules reflected the complexity and subtlety of locating findings and were flexible enough to allow for inevitable ambiguities and include specific exceptions (see Box 1.5 pp. 44-7). For example: “Statements that indicate they are portions of interview data, even though they are not direct quotations, are not findings and should not be extracted. These may begin, ‘One participant said that..’ or, ‘One participant described...’” (Decision Rule 4 of 7). Applying this rule led to the judgement that, in the following statement from one of the studies, the first two sentences were classified as findings, whereas the third sentence was classified as supporting data and was not extracted as a finding:

Participants described past life experiences and attribution of meaning to their lives. Relationships were often the focus of attribution of meaning. For example, one participant described the development of her relationships with God and others and how she was helping others in her church congregation.

To enhance validity of the process of extracting findings two researchers (myself and a professorial colleague) independently extracted findings from three papers selected at random from the bibliographic sample of twelve qualitative research reports. Each researcher used the written decision rules as a guide to extraction. There was nearly 90% consensus across all three reports. That is, approximately 9/10 of the findings extracted were extracted by both researchers. There was a variation of 10%, representing findings which were extracted by one or other researcher but not by both. Reasons for this variation included: simple oversight, competing interpretations or violation of a decision rule, or persistent ambiguity regarding status as a finding where the decision rules did not prove an effective guide. Of 25 statements initially extracted as findings by one or other researcher, but not by both, it was agreed to include 19 as findings and to exclude the remaining six (one was extracted as a simple oversight and five contravened a new decision rule). Discussion of these inconsistencies led to the writing of one new decision rule (number 7, Box 1.5 p. 47) and to creating an exception to an existing decision rule (number 1, Box 1.5 p. 44). In line with Sandelowski & Barroso's prescription all the reports were then re-read in the light of the new decision rules.

Following this process it was decided to exclude one report (Ryan, 2005) on the basis that the 'findings' were presented as 'narrative summations' (p.1101) which had the appearance of raw data. The data, derived from interviews, were edited by the researcher and presented as narratives which did not seem to be sufficiently transformed from the original data to meet the operational definition of a finding for this review.⁴

The outcome of this process of locating and extracting findings is confidence that the data set created for this research integration study, or qualitative systematic review, is genuinely constituted from the findings of the research

⁴ Reflecting on this decision several years after completion of this qualitative systematic review, and having conducted my own narrative study, I consider this exclusion to have been an error of judgement. Re-reading the paper, I think it could be said that Ryan does transform data into findings in writing about her participants' experiences of cancer. It is still not clear to me, though, how best to integrate them into the analytic process used in my review.

reports included in the sample. Four hundred and fourteen findings were located from 11 reports and were extracted to word processing files. Findings were edited where necessary to preserve the sense for readers who are unfamiliar with the whole report (Sandelowski & Barroso, 2006). Subsequently, all findings were copied into one word processing file in preparation for the stage of analysis described in Sandelowski & Barroso's framework as 'Grouping Findings'.

1.3.3 Grouping Findings

Findings were grouped by topic, in a process analogous to thematic analysis. 'Topics' are recurrent patterns, subjects, themes or motifs which are recognised through the close familiarity with the findings engendered by the previous stages of initial appraisal, locating, extracting and editing. For example, the topic of 'empowerment' was observed to recur in the findings following repeated readings. In order to group all findings on this topic a search was conducted of the findings file using the Find (Ctrl+ F) facility in Word. The text was searched on 'empower', which also retrieved 'empowerment' 'empowering', 'empowered' and 'power'. Synonyms or closely related concepts appeared while searching the text on these key words and further searches were conducted on these new terms. In the case of empowerment, the concept of 'autonomy' was related and the text was also searched on this term (plus 'autonomous'). At the same time notes were made of topics which might overlap or link with empowerment; for example, *passivity*, *patient-physician relationship*, *control*, *making choices*, *making decisions*, *information-seeking*. This process was repeated for each of the identified topics.

Findings were initially grouped into 15 topics. Table 1.5 (p.48) shows which topics featured in each of the papers. Findings on the topic of relationships with family and friends appeared in all 11 reports; findings on the topic of assertiveness only appeared in one report (assertiveness was the major topic of this particular study). In a second phase of identifying topic groupings an independent researcher read all the study reports alongside the topic groupings identified in the first phase in order to check face validity, and with the

intention of noting any potentially significant omissions from the original list. This process resulted in the identification of four additional topic groupings: age/ageing, alone-ness, meaning and limited time. The findings were interrogated again to locate findings in each of these topic areas.

1.3.4 Abstracting Findings

The grouped findings comprised a data set of approximately 20 000 words. In order to reduce the data still further in preparation for synthesis the grouped findings were explored to discover further patterns, overlaps, comparisons and redundancies. Sandelowski & Barroso's framework refers to this process as 'abstracting' the findings. This means that the findings are summarised, abridged, reduced to a form which represents their essence. Authors' original words are used except where findings are rewritten, according to decision rules, to maximise clarity. Findings are rewritten to 'render them more parsimoniously' and to produce a 'set of statements that concisely but comprehensively captures the content of all the findings and preserves the context in which they appeared' (Sandelowski & Barroso 2006 p.159). In the process of abstracting, redundancies and repetitions in the grouped findings are eliminated and finding statements are refined to make them inclusive of the ideas researchers conveyed in the findings. It is important to preserve any contradictions and ambiguities in the findings (Sandelowski & Barroso 2006). Abstracting the findings produced a data set of approximately 6000 words in five topic areas (bodily signs and symptoms, treatment, empowerment, states of mind, relationships). All the previously identified topic groupings, from both phases of topic identification, were incorporated in the dataset from which the abstracted findings were derived.

1.4 Summary

In this chapter I have presented the rationale and purpose for conducting a qualitative systematic review to investigate older people's experiences of living with cancer. I have explained in detail, and evaluated, a four-stage method used to search for relevant primary research studies. A five-stage model was used to

review the studies, following Sandelowski & Barroso (2006), whereby the published reports were appraised, findings were located, edited, grouped and abstracted to produce a dataset for subsequent analysis.

In the next chapter I present analysis and interpretation of this dataset, comprising findings from a sample of 11 qualitative research reports which investigated older people's experiences of living with cancer.

Box 1.3 Example of search including ‘filter’ for qualitative research
Search conducted on CINAHL October 13th 2006

1. *HEALTH SERVICES FOR THE AGED/ or **AGED, 80 AND OVER"/ or *AGED/ or *AGED, HOSPITALIZED/ or Aged.mp.
2. elder\$.mp. [mp=title, subject heading word, abstract, instrumentation]
3. geriat\$.mp. [mp=title, subject heading word, abstract, instrumentation]
4. gerontol\$.mp. [mp=title, subject heading word, abstract, instrumentation]
5. old\$.mp. [mp=title, subject heading word, abstract, instrumentation]
6. 1 or 2 or 3 or 4 or 5
7. exp neoplasms/
8. NEOPLASMS/
9. exp Attitude to Illness/ or exp Cancer Patients/ or exp Aged/ or exp Adaptation, Psychological/ or exp Adult/ or exp Patient Attitudes/ or exp Thematic Analysis/ or malign\$.mp. or exp Pain/
10. tumour\$.mp. [mp=title, subject heading word, abstract, instrumentation]
11. 7 or 8 or 9
12. exp chronic disease/
13. chronic illness.mp. [mp=title, subject heading word, abstract, instrumentation]
14. 12 or 13
15. experience\$.mp. [mp=title, subject heading word, abstract, instrumentation]
16. (living adj2 cancer).mp.
17. (living adj chronic illness).mp.
18. 15 or 16 or 17
19. 6 and 11 and 14 and 18
20. qualitative studies/
21. ethnographic studies/
22. phenomenological research.mp. [mp=title, subject heading word, abstract, instrumentation]
23. ethnonursing research/
24. grounded theory/
25. exp qualitative validity/
26. purposive sample/
27. exp observational method/
28. content analysis/ or thematic analysis/
29. constant comparative method/
30. field studies/
31. theoretical sample/
32. discourse analysis.mp. [mp=title, subject heading word, abstract, instrumentation]
33. focus groups/
34. phenomenology/ or ethnography/ or ethnological research.mp.
35. (qualitative or phenomenol\$ or ethnon\$).tw.
36. (grounded adj (theor\$ or study or studies or research)).tw.
37. (constant adj (comparative or comparison)).tw.

38. (purpos\$ adj sampl\$).tw.
39. (focus adj group\$).tw.
40. (emic or etic or hermeneutic\$ or heuristic or semiotics).tw.
41. (data adj1 saturat\$).tw.
42. (participant adj observ\$).tw.
43. (heidegger\$ or colaizzi\$ or spiegelberg\$).tw.
44. (van adj manen\$).tw.
45. (van adj kaam\$).tw.
46. (merleau adj ponty\$).tw.
47. (husserl\$ or giorgi\$).tw.
48. (field adj (study or studies or research)).tw.
49. (lived adj experience\$).tw.
50. narrative analysis.tw.
51. discourse\$ analysis.tw.
52. human science.tw.
53. life experiences/
54. convenience sample/
55. exp cluster sample/
56. or/20-55
57. 19 and 56

Box 1.4 Journals searched manually

Age and Ageing
Ageing Research Reviews
Ageing and Society
Cancer Nursing
Cancer Practice
Current Opinion in Oncology
European Journal of Cancer Care
European Journal of Oncology Nursing
Geriatric Nursing
Oncology Nursing Forum
Psycho-oncology
Qualitative Health Research
Seminars in Oncology
Social Science and Medicine
Seminars in Oncology Nursing
Sociology of Health and Illness
Supportive Care in Cancer

Table 1.1 Provisional bibliographic sample and location source

Report	Source ie located by....
Adler SR, McGraw SA, McKinlay JB (1998). Patient assertiveness in ethnically diverse older women with breast cancer: challenging stereotypes of the elderly. <i>Journal of Aging Studies</i> 12 (4): 331-350	Reference follow-up (Sinding et al 2005)
Duggleby W (2000). Enduring suffering: a grounded theory analysis of the pain experience of elderly hospice patients with cancer. <i>Oncology Nursing Forum</i> 27(5):825-834	Manual search
Feher S and Maly RC (1999). Coping with breast cancer in later life: the role of religious faith. <i>Psycho-Oncology</i> 8 (5): 408-416.	Manual search
Harden J K, Northouse L L, Mood D W (2006). Qualitative Analysis of Couples' Experience With Prostate Cancer by Age Cohort. <i>Cancer Nursing</i> 29 (5): 367-377	Manual search
Hedestig O, Sandman P Widmark A (2003). Living with untreated localized prostate cancer: a qualitative analysis of patient narratives. <i>Cancer Nursing</i> . 26 (1): 55-60.	Manual search
Navon L and Amiral M (2004). Liminality as biographical disruption: unclassifiability following hormonal therapy for advanced prostate cancer. <i>Social Science and Medicine</i> (12): 2337-234.	Manual search
Overcash JA (2004). Using narrative research to understand the quality of life of older women with breast cancer. <i>Oncology Nursing Forum</i> 31 (6): 1153-1160.	Electronic search + manual search
Roberts J, Morden L, MacMath S, MassieK, Olivotto I A, Parker C and Hayashi A (2006). The	Manual search

Quality of Life of Elderly Women Who Underwent Radiofrequency Ablation to Treat Breast Cancer. <i>Qualitative Health Research</i> 16: 762-772.	
Ryan P (2005). Approaching death: a phenomenologic study of five older adults with advanced cancer. <i>Oncology Nursing Forum</i> 32 (6): 1101-1108.	Manual search
Sinding C, Wiernikowski J Aronson J (2005). Cancer care from the perspective of older women. <i>Oncology Nursing Forum</i> 32 (6): 1169-1178.	Manual search
Thomé B, Esbensen B A, Dykes A-K, and Hallber I R (2004). The meaning of having to live with cancer in old age. <i>European Journal of Cancer Care</i> , 13:399-408.	Electronic search + manual search
Thomé B, Dykes A-K, Gunnars B and Hallberg I R (2003). The experiences of older people living with cancer. <i>Cancer Nursing</i> , 26 (2): 85-96.	Electronic search + manual search

Table 1.2 Summary of analytic techniques applied to extracted findings from research reports

Initial Appraisal	Reports read and appraised
Locating Findings	Definition of a finding Decision rules Locating findings wherever they appear in report Separating findings from supporting data Optimising validity by independent location of findings by another researcher in a randomly selected sample of reports (n=3)
Extracting Findings	Creating a Word file for each report into which identified findings are copied
Editing Findings	Reading extracted findings and editing where necessary to make sense for readers unfamiliar with original report, but staying as close as possible to original wording and preserving sense and context
Grouping Findings	Identifying recurring 'topics' (similar to thematic analysis) based on close familiarity with findings Optimising validity by independent researcher checking grouped topics for face validity against findings for whole sample
Abstracting Findings	Summarising findings across topics and research reports, collapsing similar topics together, representing the essence of the findings in fewer words, while preserving the original context of the reports
Descriptive Summary of Findings	Presenting abstracted findings in narrative format
Working Hypothesis	'To live with cancer in old age is to live in a perpetual state of ambiguity'

Table 1.3 Initial Appraisal Template/Reading Guide (Sandelowski & Barroso, 2006)

Face Page	Initial Appraisal	Reviewer's Summary
Full citation	Initial appraisal [brief citation]	Research purpose
Author affiliations		Theoretical framework
Funding source	Research problem	Method
Acknowledgements	Research purpose/question(s)	Sample size and key characteristics
Period of data collection	Literature review	Data collection techniques
Geographic location of study	Orientation toward target phenomenon	Data analysis techniques
Date of submission	Orientation toward inquiry	Primary topic of findings
Date of acceptance	Sampling strategy and techniques	Secondary topic of findings
Publication type	Sample size and composition	Type of findings
Mode of retrieval	Data collection or generation techniques and sources	Edited findings
Key words	Data management and analysis techniques	Evaluation (signal-noise ratio)
Abstract (copy from article)	Data Analysis and Interpretation	Summary comments
Related reports	Orientation to & techniques for maximizing validity	
Date/s of this review	Limitations	
Reviewer	Findings	
Purpose of review	Logic & form of findings	
Authored by reviewer, or member of review team?	Discussion & implications	
	Summarising/concluding	
	Disciplinary/theoretical significance	
	Clinical significance	
	Protection of human subjects	

Table 1.4 Summary data from provisional bibliographic sample

Report	Study popn	Type of cancer	Research design/methods	Theoretical framework	Study setting
Adler et al 1998 (USA)	N=29 Age 63-85	Breast cancer	Focus group interviews (4 gps by ethnic origin) 2 interviews each group	None indicated	Eastern and Western USA. Site of interviews not indicated
Duggleby 2000 (USA)	N=11 Age 65	Advanced cancer (various sites)	Grounded theory 15 interviews (2 x2; 1 x 3) 15-60 mins	Grounded theory framework but no theory generated	“for profit” hospice. interviews at pt homes
Feher and Maly 1999 (USA)	N=33 Age 65 yrs	Breast cancer, within 6 mths of diagnosis	No overall design indicated. Structured interviews with open- ended questions, 2 hrs	None indicated	8 study sites incl. comm./hosp breast and cancer clinics, private surgical and oncology outpatients. Most interviews at

LIVING WITH CANCER IN OLD AGE:
A QUALITATIVE SYSTEMATIC REVIEW AND A NARRATIVE INQUIRY

					home.
Harden et al 2006 (USA)	N= 15 couples Age 50-84 in 3 age cohorts	Prostate cancer: various phases within each cohort	'qualitative interviews' no overall design indicated	Life span development	2 cancer centres NW USA
Hedestig et al 2003 (Sweden)	N=7 men Age 62-69	Untreated localized prostate cancer	Hermeneutic phenomenology	Hermeneutic phenomenology	Interviews at home
Navon and Morag 2004 (Israel)	N=15 Age 57-85	Advanced prostate cancer, receiving continuous treatment 6mths-3 yrs	In-depth interviews x 2 @ 2 hrs each	Liminality	Oncology outpatients
Overcash 2004 (USA)	N=12 women Age 70+	Breast cancer	Descriptive study with in-depth interviews and observation	None indicated	Various sites for interview
Roberts et al 2006	N=12	Breast cancer, 4	Descriptive	Phenomenology	Not indicated

(Canada)	Age 60-81	mths-1 yr post RFA treatment	phenomenology		
Ryan 2005 (USA)	N=5 Age 65-83	Advanced cancer (various sites)	Phenomenology (Munhall) 3-6 interviews 40-160 mins each	Phenomenology	Not indicated
Sinding et al 2005 (Canada)	N=15 women Age 70+	Breast cancer (10) Gyn cancer (5)	Qualitative, participatory	Participatory research	Not indicated
Thomé et al 2004 (Sweden)	N=10 (7 women/3 men) 75 +	Various cancers just completed treatment	Hermeneutic phenomenology (van Manen) interviews 45-150 mins	Hermeneutic phenomenology	Recruited through oncology clinics Interviews at home
Thomé et al 2003 (Sweden)	N=41 Age 75 +	Various cancers	Interviews (some telephone) latent content analysis	None indicated	Interviews at home Recruitment from larger study

Canada=2 Israel=1	Age range: 50-60 = 2	Breast: 4 studies Prostate: 3 studies	Grounded theory =1 Phenomenology = 4	
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LIVING WITH CANCER IN OLD AGE:
A QUALITATIVE SYSTEMATIC REVIEW AND A NARRATIVE INQUIRY

Sweden=3 USA=6	60-65 = 3 65 = 2 70-75 = 3 75 + = 2 Total no informants: n=215 Sample range: n=5-41	Various: 5 studies	Narrative =1 Unspecified= 6	
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Box 1.5 Decision Rules for Extracting Findings from Qualitative Research Reports for an Integration Study

A finding is defined as: ‘a data-driven and integrated discovery, judgement and/or pronouncement researchers offer about the phenomena, events, or cases under investigation’ (Sandelowski and Barroso 2006; 2003).

- 1. All findings or finding-type statements which meet the definition above should be extracted in the first instance, wherever they appear in the report and irrespective of repetition.**

Exceptions/ambiguities? Finding-type statements which represent examples of findings expressed during the analytic process and which do not re-appear as findings elsewhere in the report. These represent findings-in-progress rather than actual findings and should be excluded.

Eg Thomé et al., 2004 Table 1 p 402 ‘Example of the revealing of one essential theme in an interview’

The illness means a time of unrest and distance from the ingrained social pattern and a reorientation to new demands.

This is a finding-type statement but it does not appear as a reported finding elsewhere and it is relatively clear from the context in which it is presented that it is derived from one particular stage of the analysis (‘holistic reading approach’).

- 2. If in doubt, extract and discuss.**
- 3. Direct quotations from interview data are not findings and should not be extracted**

‘Participants dealt with suffering through the basic social process of enduring. As one participant said, “You don’t manage pain, you endure it.” The first sentence is a finding, the second is not.

Exceptions/ambiguities? Statements which include one or two words in quotation marks but where the reporting voice is really the author's e.g.

'Strategies for decreasing pain fostered hope for "relief of pain" and to "not suffer more" because participants felt they were able to do something about their pain'. This is a finding.

- 4. Statements which indicate that they are portions of interview data, even though they are not direct quotations, are not findings and should not be extracted. May begin 'one participant said that..' or 'one participant described...'**

'Participants described past life experiences and attribution of meaning to their lives. Relationships were often the focus of attribution of meaning. *For example, one participant described the development of her relationships with God and others and how she was helping others in her church congregation.'*

The first two sentences are findings. The third is not.

- 5. Statements which offer authors' views on the clinical, educational or research implications of the results are not findings and should not be extracted**

'In this study, participants described their suffering as pain from cancer, other diseases, loss of physical function, feelings of helplessness, and dependency. *Because of the nature of terminal illnesses, preventing or eliminating suffering may not always be achievable. Therefore, fostering and encouraging enduring are also important focuses for research and practice.'*

The first sentence is a finding. *The next two sentences are not findings.*

6. Statements which refer to findings from other studies or from academic literature are not findings and should not be extracted

‘Participants described enduring as work that requires strength and willpower. *Fagerhaugh and Strauss (1977) defined "pain work" in their study of terminally ill patients as the healthcare professionals' role in helping patients endure their pain.* The findings of this study emphasize that the participants also had “pain work.”’

The first and third sentences here are findings, *the second sentence is not a finding.*

Exceptions/ambiguities? ‘By offering a framework for the interpretation of events and situations, strong religious and spiritual beliefs often deepen a sense of meaning (Idler, 1987; Pollner, 1989; Ellison, 1991; Pargament, 1997), a finding corroborated by the geriatric population we interviewed’ (Feher & Maly, 1999: 414).

This may be included as a finding because, although it begins with reference to another study it offers a statement which confirms that the same findings occur in the study being reported. Such findings may be re-written (Sandelowski & Barroso), being careful to preserve the authors’ original words and intentions. The present example could be re-written as follows:

‘Strong religious and spiritual beliefs offered a framework for the interpretation of events and situations which gave participants a deeper sense of meaning’

7. Finding-type statements which gloss over the substantive meaning of the finding by the authors’ use of evaluative or emotional language may be re-written using more neutral language and then extracted as a finding

Eg Duggleby: *'the findings of this study are a reminder of the incredible ability of elderly hospice patients to endure suffering'*

In this sentence the word 'reminder' invites the reader to locate themselves, with the author, in a supposed state of pre-existing knowledge whereby it is known already, independently of this research, that elderly people are stoical; and the word 'incredible' represents a value judgement about such a quality.

The finding may be re-written to represent the substance of its meaning as a finding simply by using more neutral language: eg *'the findings of this study show the ability of elderly hospice patients to endure suffering'*.

Table 1.5
Cross Comparison of Study Reports by Topic (Grouped Findings)

Topic	Article										
	Adler et al., 1998	Duggleby, 2000	Feher & Maly, 1999	Harden et al., 2006	Hedestig et al., 2003	Navon & Morag, 2004	Overcash, 2004	Roberts et al., 2006	Sinding et al., 2005	Thomé et al., 2003	Thomé et al., 2004
Assertiveness	*										
Choices	*				*			*	*	*	*
Control	*		*		*	*		*		*	*
Decisions		*			*		*	*	*	*	*
Power	*	*				*	*	*	*	*	*
Information	*		*		*	*	*	*	*	*	*
Relationships (HCP*)	*	*	*		*		*	*	*	*	*
Relationships (family, etc.)		*	*	*	*	*	*	*	*	*	*
Bodily symptoms				*	*	*	*			*	*
Pain		*				*		*		*	*
Treatment	*			*	*	*	*	*	*	*	*
Masculinity					*	*					
Mental impact	*	*	*	*	*	*		*		*	*
Religion	*	*	*		*		*				
Sexuality				*	*	*				*	

*HCP= Health Care Professional

CHAPTER 2

‘EXPERIENCING CANCER’: ANALYSIS AND INTERPRETATION OF FINDINGS

2.1 Introduction

Older people in the studies reviewed for *Experiencing Cancer* reported a range of complex impacts arising from their experience of cancer which related to a) the bodily signs and symptoms of cancer; b) decisions about whether to have treatment and the experiences of undergoing treatment; c) the extent to which they felt empowered; d) the states of mind induced by the experience of living with cancer; and e) the effects of cancer on their relationships with partners, families, friends and health professionals.

The findings are presented here at two levels of analysis: descriptive and interpretive. The first, descriptive, level stays very close to the language of the original reports in order to preserve the credibility of interpretations which are made of the studies’ findings at the second, interpretive, level of analysis. The only exceptions to this fidelity to the original authors’ language are where findings have already been edited or rewritten (Sandelowski & Barroso, 2006) according to the decision rules referred to in the previous chapter or where the narrative flow and clarity of meaning required the insertion of some linking phrases.

2.2 Descriptive analysis of findings

2.2.1 Findings relating to Bodily Signs and Symptoms

Older people in these studies experienced changes in their bodies which they attributed to cancer, to the effects of cancer treatment and to age related changes associated with normal ageing or with comorbidities. Bodily experiences included fatigue, pain, nausea and vomiting, appetite loss, urinary and faecal incontinence, alopecia and bodily feminisation (in men with prostate cancer, as

a result of hormone treatment). Older people could feel severely buffeted, worried and anxious by these experiences but at the same time put in place strategies to manage the situation. Fatigue was managed by taking time to rest and by maximising available energy. Analgesic medication for pain in terminal cancer was augmented not only by non-pharmacological means of pain relief but by a strategy of endurance based on finding hope and on adjusting to pain emotionally. Religious faith and the support of caring families provided essential underpinning support for the effectiveness of these psychological pain-relieving strategies. Adaptation to unwanted changes in physical appearance was achieved by simply avoiding the sight of the changed body or by reconstructing the difficulties to emphasise a positive side. For example, loving attention from family members sometimes compensated for the psychological pain of alopecia.

The experience of, and strength of reaction to, bodily change appeared to be heterogeneous according to age, stage of cancer and comorbid disease. For some, effective cancer treatment which had minimal impact on the body or on the person's life proved to be encouraging and made things easier. For others, physical changes could be overwhelming ("excruciating"), diminish physical and emotional strength unbearably, provoke revulsion and self-abhorrence, undermine a sense of normality and transform life into a hopeless and lost situation.

2.2.2. Findings relating to Treatment

Nine of the studies reported older people's experiences relating to cancer treatment. Decisions about treatment, including whether or not to have treatment, were affected by interpersonal, intrapersonal and social factors. Relationships with the health care personnel and with family members affected treatment decisions. For example, the approach to decision making was seen as a collaborative venture, by women undergoing radio frequency ablation (RFA) for breast cancer (Roberts et al., 2006), in which women saw their role as to be informed about the available treatments but to leave the final decision to the medical team on the basis of a trusting relationship. This was seen not as a choice to opt out of decision-making but as a preference to view oneself as only

one part of the decision-making process. It is important to note that these women were receiving treatment as part of a research study and were highly motivated towards taking an active part in the management of their disease.

For older people in other studies, making decisions about treatment was sometimes felt to be burdensome and they expected health care providers to make decisions for them, based on their superior knowledge. On the other hand, older people who did want to be consulted, or wanted to decide against treatment, and who were ignored or unsupported in their decision, regarded their health care providers as paternalistic. Such attitudes and behaviours on the part of health care personnel caused ruptures in their relationships with older people. Whatever the decision, encouragement from family members was important.

Important intrapersonal factors in decision making about treatment included the ability to exercise personal control. In some studies (e.g. Thomé et al., 2003) some older people tried to get as much information and knowledge as possible in order to make independent decisions, whereas others chose not to be informed or to seek control and to let other people make decisions for them. In the RFA study (Roberts et al 2006) the decision to have treatment as part of a research study enabled participants to gain some personal control. In a study of men and women aged over 75, decisions about treatment (for a range of different cancers) were not seen as discrete but were embedded in a wider context of the power to choose the approach to daily life with cancer (Thomé et al., 2003).

For older people, making decisions about treatment, and living with their consequences, was experienced as difficult in the light of comorbid conditions. They sometimes chose to forego treatment (Sinding et al., 2005) explicitly in the context of their age, or age-related health problems and social circumstances. Careful thought preceded decision-making. Readiness to undergo treatment showed itself in bargaining about the price to be paid in side-effects in proportion to the beneficial effect of treatment. More broadly, willingness to undergo treatment was influenced by older people's values and their perception of their whole life situation.

Decisions about treatment were influenced by social context, that is, the general attitude to cancer treatment in old age. Those in advanced old age felt that their age was a factor taken into account by health professionals in deciding treatment options, which in some cases meant limited access to various methods of therapy. Suspicions about being treated less carefully owing to old age exacerbated feelings of abandonment and uncertainty. Contrary to these unmet expectations of high-quality treatment, some older people were challenged by their peers on the value of undergoing treatment at all at that stage of life.

Findings from these studies revealed a number of strategies employed by older people for managing the process of undergoing treatment for cancer. Strategies included placing trust in the oncologist; seeking comfort through prayer; maintaining an active life; concealing the illness from anyone outside the immediate family; keeping a sense of control by being well-informed or, on the contrary, remaining passive and allowing health care professionals to be responsible for decisions about treatment and care; adapting and adjusting constructively to side-effects of treatment and residual disabilities. Maintaining an active life included, for some women undergoing breast cancer treatment, sustaining a role as primary caregiver to others.

Positive and negative effects from treatment were reported. Women treated with RFA for breast cancer reported satisfaction with treatment, which reduced anxiety about the disease and improved quality of life. They were especially pleased with the amount of information they received before, during and after treatment. Hormonal therapy for advanced prostate cancer allowed men to regain their physical strength, to retain their masculine self-identification and to renew their relationships with their spouse and with social contacts. But there were physical and psychosocial costs which affected their self-definition as healthy, sexually competent and fully male, leaving them in a liminal state. Many felt revolted by their bodily feminisation. Their pre-treatment relationships lost a sense of closeness and they felt deprived of a sense of continuity, excitements, hopes and coping capabilities (Navon & Morag, 2004). In a different study of men treated with hormone therapy for prostate cancer men

also spoke of disruption to their plans and of decreased energy and impotence caused by treatment (Harden et al., 2006). Impotence was a common result of disease (untreated localised prostate cancer) or treatment (hormone therapy for advanced prostate cancer) but reactions to this varied. For some men sexual activity was less important because of old age. For others, advanced age did not reduce the importance ascribed to the role of sex in their lives.

Treatment effects for older people in the Swedish studies (Thomé et al., 2004, 2003) were experienced against a complex background of bodily disabilities and limitations resulting from the cancer disease, from the effects of ageing (including comorbid disease) or from ageing impaired by cancer. The effects of cancer and its treatment seemed to produce the greatest limitations in daily life, however, to the extent that life became “disintegrated”: that is, more or less fully occupied with travelling to undergo treatment, residing away from home for the duration of the treatment, then coping with the side-effects of treatment, not only on the body but on social life and relationships. These experiences provoked existential, as well as physical and emotional, suffering.

Despite these difficulties, older people with cancer felt that it was possible to endure their experiences and to accomplish the tasks required of them in order to face the illness and its treatment. Illness experience presented an unexpected consciousness of the personal power and strength to have gone through a tough period of illness and treatment which forced them to reappraise their life. Despite its difficulties, the value of having undergone treatment was appreciated as time went on. In the anticipated future there was a reorientation and re-entry to ordinary social life, but with a new experience added.

2.2.3. Findings Relating to Being Empowered

Eight of the studies reviewed contained findings relating to empowerment. A continuum was evident in which older people were empowered or disempowered to varying degrees according to their own attitudes and actions or the attitudes and actions of others. Participants in the studies were empowered by an attitude which represented an internal locus of control, through their self-directed assertive behaviour or through the supportive actions of others.

Self-empowered attitudes included a feeling of responsibility for one's own health, and the unexpected consciousness of the personal power and strength to have endured a tough period of illness and treatment. Self-empowered behaviour included employing a range of assertive strategies in encounters with physicians, such as: information seeking, insisting on comprehensive and efficient treatment and management of their illness and, as a last resort, changing to a different physician if they were not satisfied. Participants felt empowered by health professionals when they felt listened to and believed in, when they were given a choice to take part, or not to take part, in discussions and decisions about treatment. A contrary finding, seen in just one study (Sinding et al, 2005) is that the invitation to make a treatment decision in the face of multiple health problems was seen as burdensome rather than empowering. It was seen as ironic that such a complex decision should be left to a patient, despite the physician's clearly superior knowledge.

Participants were disempowered by an attitude which represented an external locus of control, by their passive behaviour or by negative attitudes and actions of health care providers. Extreme feelings of disempowerment were reported by some participants from the point of diagnosis as life was perceived as suddenly and wholly surrendered to the trust of healthcare personnel. This was experienced as a disintegration of the life situation. Passive behaviour on the part of older people was seen as disempowering when it was enforced, rather than actively chosen, because they felt a lack of options due to their poor health. Passivity was not always disempowering; sometimes it was a route chosen by older people to get what they wanted. Health care providers reinforced feelings of disempowerment when participants felt they were being neglected on the grounds of their age.

2.2.4. Findings Relating to States of Mind or Feeling Associated with Living with Cancer

Nine of the studies reviewed contained findings relating to states of mind or feeling which accompanied older people's lives with cancer. They expressed a range of negative and positive emotions including uncertainty, fear, anxiety,

insecurity, depression, despair as well as confidence, hope, safety, reassurance and peace. Older people described fear and worry when they were first told that they had a tumour and that they had to have regular check-ups. An unsympathetic attitude from the physician at this early stage meant a violating experience leading to anxiety, sleep disturbance and feelings of dejection. There was uncertainty about the relative roles of cancer, other illnesses and of age itself in producing symptoms and disabilities. Lack of information about the disease was discouraging and became a source of fear of progressive disease and death. Uncertainty was described as living in a “shadow land” (Hedestig et al 2003). When older people wanted information but could not acquire it they felt insecure and out of control. Symptoms such as appetite loss, nausea and vomiting caused them to worry about nourishment and about their dependence on others. They feared the physical side-effects of treatment and worried about what would happen when side-effects appeared.

It was not only the impact of the cancer on the body which caused negative emotions. Relationships with relatives, friends and health professionals, in many ways sources of support, could also produce anxiety and fear: for example, fear of rejection by family and friends or fear of retribution by physicians in response to assertive behaviour.

Thoughts about the future hovered between hope and despair. Hope was important as a way to endure cancer and arose in the treatment phase from absence of signs of the cancer along with positive information from the doctor. At a later stage of disease older people expressed hope that the end of life would come soon. Despair arose from feeling abandoned and uncertain about how future life would be affected by the cancer. There were fears of becoming dependent on help for daily living and expressions by couples of a nagging worry about their future together. A contradictory finding in the face of anxieties about the future is that, in regard to expectations of how much time was left, older people had realistic presumptions about future time and mostly met the probability of a foreshortened life with no fear. Death itself was sometimes feared and sometimes viewed as a release, but the process of dying was feared

as older people anticipated excruciating symptoms, confinement to bed and dependence on others.

Resources and strategies for replacing feelings of uncertainty, fear and anxiety with feelings of confidence and assurance included older people's own chosen attitudes, as well as specific behavioural strategies. Attitudes included: acceptance of pain; acceptance, without fear or sadness, that a long and eventful life was coming to a natural end; hoping for relief of pain, an end to suffering and life after death; endurance of suffering; trusting in a higher being, confidence in God, belief in fate. Faith brought comfort, security, assurance, peace, tranquility, serenity, lack of fear and thankfulness. Having a good understanding of their disease, effective treatment and strong relationships with family, friends, healthcare providers and other patients also played a role in boosting feelings of safety and confidence.

Behaviours to combat negative emotions included: adjusting to pain by consciously diverting the mind from it; deciding to undergo a treatment which would kill the tumour; "binding" anxiety by focusing on others and praying for them; screening off or setting aside the experience of threat; denying that the cancer cells still existed; compensating for the threat by making lifestyle changes; remaining distanced from the disease by not talking about it; and presenting a picture of the self to family members and caregivers as safe, happy and unafraid.

2.2.5 Findings Relating to Relationships

More than one third of all the abstracted findings relate to study participants' relationships: with their life companions, family, friends, communities and health care providers. All the studies reviewed contained findings about relationships in the context of living with cancer.

Intimate relationships with spouses changed as a result of living with cancer and adaptation to change was needed in order for couples to maintain the quality of their life together. Couples interviewed together about the experience of living

with prostate cancer (Harden et al., 2006) expressed a deeper sense of closeness but noted that living with the disease required them to learn a new way of living together every day. Couples agreed that open communication was essential to adjust to changes in their normal intimacy patterns. Being able to confront their problems and talk about them together helped them to overcome denial and move toward acceptance. Facing facts and talking about options seemed to make life easier to manage. Older couples referred to prostate cancer as a couples' disease.

Changes in sexual desire and function related to the cancer disease or its treatment had a variable impact on spousal relationships. For most men with untreated localised prostate cancer the symptoms of the disease (i.e. impotence) had not affected their sexual relationships with their wives, but they often chose not to discuss their illness with their wives in order to protect them from worry. In a study comparing three cohorts (late middle age; young-old and old-old) older (i.e. the "oldest old") couples raised less concern about erectile dysfunction than late middle age or "young-old" couples (Harden et al., 2006).

Men treated with hormone therapy for advanced prostate cancer had dramatically different experiences. Referring to their partners' attitude towards their physical condition (i.e. feminised appearance resulting from hormone therapy), some of the research participants related that they had moved into separate bedrooms due to their spouses' revulsion, fear of infection, refusal to share the marital bed with them, and insistence on taking away their authority in running the household. The cultural context of this study (Navon & Morag, 2004) seems to be one in which Israeli men express pride in their masculine power and in their successful occupation of typical male roles. Other participants, in contrast, reported that besides displaying care and affection, their partners had encouraged them to leave the division of roles unchanged, to participate in joint leisure activities and in non-coital sex (Navon & Morag, 2004).

Increasing disability and dependence made some older people worry about the strain put on their partners and created anxiety about the spouse's future life

alone. At the same time as awareness of vulnerability, however, there was a strengthened relationship between some spouses which resulted in feelings of confidence in meeting future challenges together.

Changing relationships with family members had both positive and negative aspects. Participants identified caring family members as helping them with uncertainty and alleviating struggles in daily life by giving consolation, comfort and confidence. They expressed a need to remain close to family members and enjoyed the more frequent visits which resulted from their illness. Even where geographical distance precluded regular visiting, many participants considered family support, most often from their adult children, as being vital to their survival. They also valued contact with grandchildren, which gave them a sense of engagement with a world outside of their own limited life space. Relationships with the family were interpreted in new ways. Families' capacity for loving care appeared to be unexpectedly great and this was seen as something that would not have been disclosed if the person had not contracted cancer. The strength to handle life with cancer, derived from supportive family relationships, gave illness a new meaning and transformed it to a positive experience. In addition to receiving support from their families, participants sought to protect family members from the cancer, and relieve their sense of being a burden, by not letting the cancer dominate in conversation; by preparing for approaching death by giving things away, putting things in order and by praying for them.

Where misunderstandings arose concerning various changes caused by the disease, taking up an undramatic attitude toward the disease, and talking openly about cancer, reduced misunderstandings and fantasies. Some participants, however, hardly ever talked to their families about their situation. Though they expressed a need to share their experiences with other people, and talked with other patients, they expressed sorrow that family members so seldom asked about their health. This made them feel even more alone with their experiences of the disease. Loneliness could also arise through dramatic challenges to the sense of self experienced in the "liminal" state induced by hormonal therapy for advanced prostate cancer. Loneliness was experienced, too, through widowhood

or being the only survivor among family and friends. But solitude also brought positive feelings of independence and an appreciation that certain aspects of daily life could run more smoothly.

Participants frequently found support in their friends and social networks, including fellow sufferers. They also used their friends' health and state of life as a comparison to measure how they were doing, a process of "downward comparison" (Thomé et al., 2003). They usually compared their own situation favourably, no matter how bad they felt it to be, with their perceptions of others'. Church communities offered a good deal of support to older people living with cancer. People felt connected to their church communities through prayer; both being prayed for and praying for others, including their health care providers; through a sense of belonging to something that had lasted for generations and through individual friendships. Church also played a significant role in socialisation (i.e. having a social life) for many older people, particularly those living alone.

For some it was important to talk to other patients with cancer about their disease, the prognosis and their physician's comments on their progress. Sometimes, though, there was ambivalence about whether to involve other people. Some participants chose not to disclose their malignant disease to friends and relatives beyond the immediate family because they feared relationships would be negatively affected, believing that people prefer to stay away from cancer sufferers.

Relationships with health care providers were reported both positively and negatively. Healthcare professionals were said to be important by being available. Their efforts to treat older people with candour, honesty and thoughtfulness led to feelings of security and hope. Positive relationships with physicians and oncologists were marked out by a sense of trust. Some older people described their relationships to their physicians as close, like a friendship. Successful encounters with physicians and other health care providers were comfortably paced. Older people were affirmed in such encounters by being believed in and listened to. Being invited to participate in

discussions and decisions about treatment was experienced as a respect for autonomy which was supportive and affirming.

Relationships were damaged or ruptured, in contrast, when older people felt unsupported in their autonomous decisions (not to have treatment, for example). If the life situation aroused feelings of abandonment and uncertainty about how illness would affect future life, suspicions about being treated less carefully owing to old age added to those feelings. Unreasonably long waiting times and vague information from the physician were interpreted as a consequence of low priority because of age. When evident signs of a cancer disease were neglected and explained as age-related it was felt to be insulting and unacceptable. Experiences of information being withheld and suspicions about dishonesty led to distrust of healthcare professionals.

2.3 Interpretive analysis of the findings

2.3.1 A working hypothesis: ambiguity

A positive-negative dichotomy relating to a range of reported experiences was detected in the findings from the studies reviewed. Close familiarity with the findings as a whole suggested the working hypothesis that to live with cancer in old age is to live with perpetual ambiguity. This hypothesis was investigated in the hope of producing more penetrating insights by exploring what Sandelowski and Barroso (2003b) call “dimensions of contrast” in the findings, or what Elofsson & Öhlén (2004) represent as “dialectical experiences.” Such contrasts were presented by authors using the stylistic phrasing “on the other hand . . .” or, “on the one hand . . . and/but on the other . . .” or, as a variant, “at the same time.” For example:

The patients interviewed said in their narratives that they were well informed about their cancers and their prognoses. They knew that their prostate cancers were localised and, together with their physicians, they had chosen watchful waiting because their tumors were “benign.” On the other hand, they spoke about a feeling that the cancer tumor might still run their lives and lead to death (Hedestig et al., 2003:58).

The theme of ambiguity is represented by other linguistic and conceptual devices as well. Metaphors of darkness (“shadow land,” Hedestig et al., 2003), fracture (“disintegration,” Thomé et al., 2004) and the concept of liminality (living on a threshold of “betwixt and between,” neither one thing nor the other; Navon & Morag, 2004) presented the experience of ambiguity at the heart of living with cancer in old age. Examples of this condition of profound ambiguity were found across the disease spectrum and the age range, including untreated localised disease, active treatment for various cancers and the post-treatment state following hormone therapy for advanced prostate cancer.

Even where specific findings presented an experience, say, of unequivocal suffering, for example, excruciating bodily symptoms (Thomé et al., 2004) or spousal rejection (Navon & Morag, 2004), other findings produced a similarly unequivocal account of a positive aspect of living with cancer; for example, the comforts provided by religious faith (Feher & Maly, 1999). Sometimes a single experience carried both positive and negative connotations; for example, hair loss from chemotherapy brought painful challenges to body image but at the same time renewed loving attention from the family (Thomé et al., 2003). Exploring dimensions of contrast across the findings as whole, therefore, confirmed the ambiguity hypothesis.

2.3.2. An ‘imported concept’: biographical disruption

I also interpreted the findings from this review in the light of the concept of biographical disruption in chronic illness (Bury 1982). Sandelowski and Barroso present the use of “imported concepts” as an interpretive device in the synthesis of qualitative findings (2006). My reading of this is that review findings can be usefully investigated in the light of concepts established in related fields of research. Bury articulated six features of the experience of rheumatoid arthritis which combined to disrupt normal life. Biographical disruption has since been investigated in relation to a range of disease and illness states (Green et al., 2007; Hopkins, 2004; Rajaram et al., 1997; Richardson et al., 2006) and in

some research the concept has been contested and modified (Carricaburu & Pierret 1995; Faircloth et al., 2004).

Because cancer is increasingly regarded as a chronic illness⁵ the review findings were explored in the light of Bury's categories in an attempt to determine the extent to which living with cancer in old age represented a biographical disruption, conceptualised as comprising: i) the experience of pain and suffering, and the fear or anticipation of death; ii) the disruption of normal relationship rules of reciprocity and mutual support; iii) re-examined expectations; iv) disrupted assumptions, with a focus on new attention to the body; v) fundamental rethinking of biography and self-concept and vi) mobilising resources as a response to disruption (Bury 1982).

2.3.2.i Pain, suffering and death.

Pain, suffering and death were apparent across the review findings. Physical pain was typically experienced towards the end stages of a cancer disease (Duggleby, 2000) or as a side-effect of treatment (Thomé et al., 2003). Some older people were able to put strategies in place, in addition to taking prescribed medication, effectively to manage pain; for others, pain was excruciating and overwhelming.

Psychological pain comprising uncertainty, anxiety and fear ran through the whole experience of living with cancer, from diagnosis, through treatment, to approaching death. With regard to death, these findings suggest that death in itself was not feared by the very old, especially when it completed a fulfilled life, but the process of dying, and leaving loved ones behind, was very much feared. Imminent death was feared if the cancer was experienced as sudden.

2.3.2.ii Disruption of normal relationship rules of reciprocity and support.

With the exception of some startling examples of alienation in personal relationships brought about by the experience of cancer and its treatment

⁵ Though this idea has been contested. See Tritter & Calnan, 2002.

(Navon & Morag, 2004) and some evidence of social withdrawal (Thomé et al., 2004), findings from these studies suggested the reverse of this kind of disruption, indicating rather a *biographical flow* (Faircloth et al., 2004). Relationships with family, friends and other support networks were at the least maintained, and were sometimes enhanced, during the experience of living with cancer. Such relationships provided a vital means of continuing support, physical, emotional and practical, for the studies' participants. Support did not always flow one way; the relationships could also involve reciprocity, with the cancer sufferer offering practical (Overcash, 2004) and spiritual (Feher & Maly, 1999) help to family and community members.

Relationships between patient and healthcare provider also proceeded smoothly in most cases. Physicians were seen as friends and as partners in decision-making (Hedestig et al., 2003; Roberts et al., 2006). Older people confidently sought information, or chose to remain in ignorance, according to their own perceived needs. There could be disruption though, when participants made a decision against treatment (Sinding et al., 2005; Thomé et al., 2003). This ruptured the unwritten contract whereby physicians offer treatment, sometimes recommend it, and patients accept the treatment. When older people decided against treatment the healthcare providers' response was sometimes unsupportive.

2.3.2.iii Re-examined expectations.

Study participants reported changes in their expectations of present and future life, from alterations to daily activities necessitated by limitations caused by disease or treatment to the anticipation of a foreshortened lifespan. Variation in changed expectations could be seen even within one study population (Harden et al., 2006). For some participants in this study cancer caused minimal disruption to their daily plans, whereas for others the effects of the disease and treatment, fatigue in particular, had a big impact on daily life. A positive finding in relation to re-examined expectations was also reported by Harden et al (2006) to the effect that a cancer diagnosis helped couples to set new priorities and more meaningful goals for themselves.

2.3.2.iv Disrupted assumptions, with a focus on new attention to the body.

Cancer, inevitably though variably, brought a disruption of taken-for-granted assumptions about the body and forced a reappraisal of its capabilities and its relation to the self. Hormone therapy for advanced prostate cancer resulted in a feminised body which, for Israeli men who prided themselves on their masculinity, was deeply disturbing (Navon & Morag, 2004). A combination of cancer, cancer treatment and old age itself, led to the familiar body becoming transformed into a disobedient body, a vulnerable body, an unreliable body, a body forced to endure (Thomé et al., 2004). For some participants effective treatment, with limited side-effects, softened the impact of cancer on the body and permitted the maintenance of an active lifestyle (Overcash, 2004).

2.3.2.v Fundamental rethinking of biography and self-concept.

Some participants in these studies had a strong self-concept which was not challenged by their disease but rather became a resource underpinning their adaptive response. Women with breast cancer who were self-empowered and assertive (Adler et al., 1998) or whose existing religious faith gave meaning to their illness (Feher & Maly, 1999) reveal biographical flow (Faircloth et al., 2004) rather than biographical disruption. For others, most noticeably men treated with hormone therapy for advanced prostate cancer, the psychosocial effect of treatment was to place them into a state of “liminality” which became a permanent, immutable state, leaving them in a condition of no longer knowing who they were (Navon & Morag, 2004). Renegotiation or reconstruction of their masculine identity did not seem available to them (Maliski et al., 2008).

2.3.2.vi Mobilising resources as a response to disruption.

Bury (1982) writes that “the disruption of friendship and community involvement arises not only because of functional limitations . . . but also because of the embarrassment which such disabilities create” (p 175). There is certainly evidence in the studies reviewed that functional limitations and embarrassment acted to disrupt both family and social relationships (Thomé et al., 2003; Harden

et al., 2006; Navon & Morag, 2004) though this could be temporary (Thomé et al., 2003). At the same time, study participants engaged in a wide range of coping strategies (Duggleby, 2000; Hedestig et al., 2003) in which they marshaled their inner resources as well as activating their community networks (church, fellow patients) to support them.

I conclude that the findings from the studies reviewed do reveal elements of biographical disruption, both to the life course and to the sense of self, in the lives of older people with cancer. But the effects of disruption were modified by the maintenance, in some cases the enhancement, of family and other support systems and by the inner resources brought to bear by participants on their changed situation. Disruption was sometimes softened, too, by experiences of biographical flow (Faircloth et al., 2004) in which participants responded to their illness in a way which revealed continuity with their former selves. The central finding of this review, the experience of profound ambiguity at the heart of experiencing cancer in old age, pertains also to the application of the interpretive concept biographical disruption: older people experienced both disruption and continuity in their lives with cancer.

2.4 Summary

The analysis and interpretation of findings in the studies reviewed suggested that the experience of living with cancer in old age was characterised by profound ambiguity. On the one hand life comprised a sense of disintegration, diminished identity, suffering and social retraction. At the same time these experiences were balanced by sources of comfort and strength found within the self and among relationships with family, friends, health care providers and community. These findings (of ambiguity) have been echoed in studies of older people living with disease other than cancer (Elofsson & Ohlén, 2004) and in a mixed population of people (aged 39-79) living with cancer (Little et al., 1998).

Although it might not be inherently surprising or novel to find that older people experienced, for example, a high degree of uncertainty when living with cancer, or that daily life comprised a fractured set of realities, the detailed accounts of

what their experiences meant for them, and the ways in which they responded, have been clearly identified by this method of systematic review and shown in the description and interpretation presented here. The findings from this review reveal the multidimensional nature of older people's experiences of living with cancer, throwing into sharp relief both the sources of suffering endured and the resourcefulness and resilience (Nygren et al., 2007) older people bring to managing a changed life.

The studies reviewed revealed both positive and negative findings relating to clinical practice. Some health professionals, for example, established strong caring relationships with older people who have cancer. In some cases physicians even came to be seen as friends by their patients. But, sometimes, it was reported that older people felt discriminated against on grounds of their age. It is not clear from the findings why such feelings arose or if discrimination, in fact, took place. What does seem clear is that older people appreciate and value a facilitative and empowering approach, which is respectful of their unique personalities and life circumstances, to discussions about their diagnosis and about available treatments. At the same time, some older people's wishes to receive direction and guidance from people they perceive to be the experts should be respected. Ascertaining older people's wishes in this regard requires careful and individualised assessment (see Chapter 7 for a consideration of this in relation to findings from my empirical study).

Health care professionals also may need to introduce flexibility into health care systems and processes in order to take account of older people's particular needs. For example, the debilitating effects of cancer treatments and of comorbid conditions may have implications for the timing of hospital attendance for treatment and follow-up, and for support of older people during their hospital visits. Finally, for health care professionals who are predominantly in younger age groups, a leap of imagination may be needed to enable genuine empathy with people whose life situation may be one of profound existential challenge.

I undertook this review because I discovered, to my surprise, that very little primary research has been conducted in this important field and, significantly, no qualitative studies of older people's experiences of cancer were identified in the United Kingdom. There is scope for more research which investigates the subjective experience of living with cancer in old age. I followed up this systematic review, therefore, with an empirical study, using narrative methods in a series of face-to-face interviews with a population of people aged 75 and older living in the North West of England. In the next two chapters I report the purpose, design and methods of this study.

CHAPTER 3

‘CANCER STORIES’: RESEARCH DESIGN, ETHICAL CONSIDERATIONS, SAMPLING AND RECRUITMENT

3.1 INTRODUCTION

In this and subsequent chapters I report the background, purpose and conduct of a narrative study which I carried out to follow up my literature-based study with empirical research in a UK population of older people with cancer. I will refer to this study by the brief title *Cancer Stories*. In this chapter I describe and justify the research design and present the approach taken to ethical considerations. I detail the sampling and recruitment procedures and present brief biographies of the study participants. In order to preserve participants’ anonymity all names used are pseudonyms and identifying details have been changed. In the next chapter I give an account of the methods used to generate data for the study and of the methods chosen for data analysis.

3.2 Background and purpose of the research

Cancer Stories is an exploratory, descriptive investigation of older people’s experiences of living with cancer. Since older people’s subjectivity is missing from research on older people and cancer (see chapters 1 and 2) I chose to use a method which would privilege participants’ own accounts of their cancer experiences and their lives, told in the form of a story or series of stories. Frank (1995) argues forcefully that stories of illness are told to be heard, not to be analysed.⁶ If the reason for eliciting the story is an avowedly therapeutic one then I would agree with this. Where stories are sought for research purposes, though, the story has a wider purpose than the celebration (Atkinson, 1997; Atkinson & Delamont, 2004) of the teller’s experience. Its purpose is to produce

⁶ Many fora now exist for people to tell stories of illness. Bingley et al (2006) reviewed patient narratives of illness published in book form from 1950 onwards. Most of these narratives were by professional writers, journalists and academics. With the rapidly increasing use of the internet, however, many stories of ‘ordinary people’ are now available via websites such as <http://www.healthtalkonline.org> and www.pilgrimproject.org and, more informally, on many individual blogs.

knowledge; therefore, analysis and interpretation of the story are required (Thorne, 2009).⁷

Having said this, social research is not conceived and conducted in a moral vacuum and a motive force behind this study was to enable the voices of a hidden population of cancer sufferers to be heard. I assumed *pacé* Vincent (1999) and Asquith (2009) [see Introduction] that the current life experience of people over 75 with cancer, and probably with comorbidities as well, would, indeed, be characterised by suffering. My research had a partly moral purpose in seeking to describe this suffering and present it to audiences whose knowledge would thereby be increased and who would be motivated to work towards reducing suffering in this population.⁸

Without distracting from the moral purpose, these assumptions must be open to challenge by a more subtle understanding of social reality and of the possibilities for eliciting any kind of ‘truth’ through the medium of a face to face research interview (Potter, 2006; Seale, 2006). It would be naïve to assume that I can present the ‘voices of older people’ directly and unmediated. Even raw interview transcripts (*pacé* the oral history work of Studs Terkel) represent an artefact that is co-constructed, the output of an interaction between interviewer and informant (Gubrium & Holstein, 2009; Silverman, 1997; Tangaard, 2009) which is then rendered in particular ways by the act of transcription (Riessman, 2008). Interviewing is not an epistemologically neutral act. And it is not morally neutral. The job of the interviewer is to listen, try to understand and to ‘retell it afterwards’, in a balanced and non-judgemental way (Bourdieu 1993, p61).

⁷ In Phoenix et al.’s (2010) typology I tend towards the stance of *story analyst* rather than *story teller*. As a story analyst I am orientated towards a standing back from the narrative data, the stories generated in interviews, with the intention of making general and comparative explanatory statements about them. At the same time, though, I hope to achieve some of the storyteller’s (ie analyst-as-storyteller, as distinct from the respondent-as-storyteller) goals of evocation and engagement with stories, letting them speak for themselves and allowing interpretation to be shown as well as told.

⁸ Though Riessman urges caution in the enterprise of research as empowerment (2008, p199).

3.3 Research Design

A social movement is underway which reveals a shift from the world in which doctors and nurses were divided from patients on the basis of their superior knowledge and expertise, a world in which decisions were made *for* patients, not made *with* them (Boote et al 2002; Hughes, 2006; Stevens et al 2003). Some older people appear to regret the passing of that world and still want to have important decisions made for them (Hughes et al 2009) but there appears to be forceful societal change developing in which consultation and shared decision-making is becoming the dominant characteristic of the relationship between health care providers and the public (Allsop et al, 2004; Brown & Zavestoski, 2004; Souhami & Tobias, 1998; Turner & Beresford, 2005). Such ‘consumer involvement’ is increasingly encouraged (Tritter, 2009) or even mandated, in all parts of the research cycle.

Against this background I sought ways to gain the views of people affected by cancer about the purpose and methods of my study. Drafts of my research proposal were reworked over a period of months following comments received from members of Consumer Research Panels⁹ (CRP) in four of the National Cancer Research Network Areas in England: North Trent; North and East Yorkshire and Northern Lincolnshire; Surrey, W. Sussex and Hampshire; Central South Coast. I also consulted with a Cancer Partnership Group in the Lancashire and South Cumbria Cancer Network where I planned to conduct the study.

Overall, there was a strong sense in the feedback received that panel members affirmed the purpose of the research, though most of the CRP members were not in the target population of people aged 75 and older. I received particularly helpful commentary on draft interview questions from a 78 year old man with prostate cancer. He warned that one or two of the questions sounded like those

⁹ ‘Consumer Research Panels are groups of consumers - meaning cancer patients, carers, and other people affected by cancer - who work with cancer researchers in a variety of ways with the intention of improving the relevance, quality or conduct of a research study. CRPs gather together people affected by cancer who wish to be involved in cancer research, and who can provide an easily accessible, expert resource for researchers and also a forum through which to pursue consumer-led projects.’
http://ncrndev.org.uk/index.php?option=com_content&task=view&id=73&Itemid=120 Accessed Sept 2nd 2009.

of a younger person who did not understand the world in which an older person had grown up. I was mindful of this advice when designing the interview method for the study.

I also sought the views of senior clinicians at the chosen research site, a Cancer Centre in the North West of England. Discussion with the Lead Clinician for the Cancer Research Network led me to a decision whereby the study population would be comprised of people aged 75 and older suffering one of the four major cancers in the United Kingdom: breast, colorectal, lung and prostate.

Presentation of my research proposal at a weekly multi-disciplinary and multi-professional meeting of clinical staff brought an enthusiastic response and the promise of help with recruitment which was richly fulfilled.

Early formulations of research questions focused on the experiences that older people have of living simultaneously with cancer and with one or more diseases characteristic of old age (eg chronic respiratory disease, cardiac disease, diabetes). Over a period of time (see commentary below on ‘emergent thinking’) the questions became modified to focus more broadly on the experience of living with cancer. Ultimately, the final research question for the study became: ‘What are the subjective experiences of living with cancer described by men and women aged 75 and older?’

Early influences on the research design were a combination of Robson’s (2002) explication of the distinction between fixed and flexible designs and Lincoln and Guba’s (1985) ideas about naturalistic inquiry. Fixed designs are appropriate to questions looking for cause and effect, for measurement and so on (randomised controlled trials and other experimental designs). Flexible designs are appropriate to more open ended questions in which phenomena are loosely or ill defined at the beginning. For Lincoln and Guba ‘the naturalistic inquirer is almost always in the position of not knowing what he or she doesn’t know’ and so ‘it would be foolish to expect the naturalist (sic) to be able to describe a design in any thing other than broad brush process strokes before the study is undertaken’ (1985 p298). Of course, as Lincoln and Guba make plain, it is important that a clear design is ultimately discernible.

A particularly important feature of these ideas was that, in an exploratory inquiry, the research design is allowed to emerge over a period of time (as a result of reading, thinking, discussion, writing) rather than be predetermined. It was clear from the outset that a qualitative (or flexible, or naturalistic) design was appropriate to this study. But the initial research questions for the study, focused on self-reported experience of participants, are answerable by a number of qualitative methods, including grounded theory, phenomenology, ethnography, narrative inquiry. After much reading, thinking and discussion I chose to use narrative and biographical methods.

There are at least six reasons why narrative emerged as my first choice from among the family of qualitative methods: i) my experience of life history interviewing (see Clark et al 2005); ii) the growing interest and expertise in narrative methods in the university department of my doctoral registration; iii) my previous intellectual interests in the structure of stories and in language; iv) Macmillan Cancer Support (my research sponsor and funder) and other stakeholder interests in hearing patient stories to influence service development from the user perspective; v) attractiveness of a field in which there is a diversity of approach; vi) exciting and stimulating encounters with narrative researchers and narrative research (eg Sparkes & Smith 2005).

Finally, the overall approach to the narrative inquiry reported here was strongly influenced by Clandinin & Connelly's (2000) conceptualisation of the 'three-dimensional narrative inquiry space' focused on the dimensions of time, place, personal and social context. Methods of data generation were strongly influenced by the Biographic-Narrative-Interpretive Method of interviewing (Wengraf, 2001). These approaches are described and analysed more fully in the next chapter.

3.4 Ethical considerations

The primary ethical considerations in this study concerned the perceived benefits of the study to be balanced against the risk of harm, conceived principally in terms of the potential for causing emotional distress by talking

about cancer. The protection of individuals' privacy was also deemed to be important as was their physical and emotional comfort during the interview.

3.4.1 Perceived benefits of the study

Cancer research has a high public profile in the United Kingdom, in particular through the activities of Cancer Research UK. Much of the research activity brought to the awareness of cancer patients and the public is concerned with the search for effective treatments. There is a powerful incentive for individuals suffering from cancer to take part in such studies. I made it clear to potential participants that taking part in my study would not have a direct benefit on their health or any impact on their treatment. This was achieved by providing written information supplemented by discussion, in which the purposes and methods of the proposed study were expressed as clearly as possible (Participant Information Sheet at Appendix 2, p. 253).

3.4.2 Privacy/confidentiality

It is important in any research interview in which people are asked to reveal their personal thoughts, feelings, ideas or experiences that participants are able to be assured that their recorded statements are kept private and confidential. (Exceptions to this occur in oral history interviewing where it may be mutually agreed that interviews are made available to a wider audience). Participants in this study were assured of confidentiality. In practice this meant that I, and all collaborating researchers or clinicians who might have access to my research data, promised not to divulge participants' personal details, or the content of the interviews, to any third party not connected with the research study. In addition it meant taking steps to ensure that all personal and interview data were stored securely, in locked filing cabinets or on password protected electronic systems. Permission was sought specifically from each participant to record the interview on digital audio recording media. Audio recordings were transferred to computer at the earliest opportunity following the interview and were password protected. Transcripts of interviews were made anonymous, as were any statements made by participants during interviews which are reported

in the research findings. Written consent to participation in the study was sought and gained from each participant (Consent Form at Appendix 4, p. 258).

3.4.3 Discomfort (physical) during interviews

Participants in this study were older men and women who by virtue of their inclusion in the research were suffering from diseases, that is, the objective presence of pathology, of various kinds. The extent to which they would be suffering illness, that is the subjective experience of symptoms, at the time of recruitment to the study and participation in interviews was unpredictable. Several recruits (see below, p. 79), having agreed to participate, withdrew before interview as they became too unwell to take part. Measures to minimise any physical discomfort to participants during the process of the interview included: i) reassurance that participation was entirely voluntary and that the participant could withdraw if feeling unwell enough to participate (or, indeed, for any other reason) either before or during an interview; ii) negotiating the venue for the interview with each individual (in the event, all participants chose to be interviewed in their home); iii) participants were invited to consider how best they might be helped to manage their participation in the interview in the event of their becoming tired. Stanworth (2004) found that her fears of overtiring participants were unfounded, citing one terminally ill 76 year old interviewee who was surprised to find that what he thought had been a pleasant twenty minute conversation had, in fact, lasted nearly 1½ hours. In *Cancer Stories* only one participant found it necessary to terminate the interview (after 57 minutes) due to breathlessness caused by her asthma. We began the interview with an agreement that she could stop talking when she felt unable to continue. She paused for a few moments after about twenty minutes, while her husband made a cup of tea, and then voluntarily resumed the interview.

3.4.4 Distress (emotional) during or after interviews

Talking about painful experiences can be therapeutic but it can also be distressing. It was important that people who were being asked to talk about their experiences were made aware that either of these reactions may occur.

On the one hand, positive feelings may come from being listened to, and possibly seeing experience in a new light as a consequence; on the other hand, negative feelings of renewed pain may arise as distressing experiences are retold and imaginatively relived. Participants in this study were informed about these important matters in the information leaflet they received before agreeing to take part in the research (see Appendix 2, p. 253). The following extract from the research protocol submitted for ethical review demonstrates the approach taken in the study:

Should the recollection of painful experience during the interview become distressing the interviewer (NH) will honour the person's experience by pausing the interview and giving the participant time to express their feelings if they so wish. If the participant is too upset to continue the interview then the interview will be terminated. Participants will be assisted to make the decision that best meets their own needs. Should this situation occur the researcher (NH) will use skills gained from many years of nursing and of pastoral work in education to comfort the participant. If distress persists beyond termination of the interview participants will be referred to the cancer care team at the local hospital for further support. At all times the participant's needs will take priority over the demands of the research. It is worth noting that in Stanworth's study (2004) of spirituality at the end of life, using in-depth interviews with people who were in some cases within days of their death, the occurrence of emotional distress was rare.

During the interviews one participant became tearful on two occasions while recalling being given her diagnosis. Three participants became tearful on talking about the deaths of their wives (all from cancer). I responded to this with attentive listening and expressions of sympathy. In all cases the distress evoked by their memories appeared to be transitory. There was no sign of residual emotional discomfort at the end of the interviews.

Ethical approval for the *Cancer Stories* study was sought from the Lancashire and South Cumbria Research Ethics Committee and was granted in May 2007.

Research governance approval was granted at the same time by the Research and Development directorate of the local hospital Trust. The research proposal and protocol submitted for ethical review can be seen at Appendix 1, p. 237).

There is a tension inherent in submitting a proposal for naturalistic inquiry, in which it is usual (see Lincoln and Guba 1985) for the design and methods to be depicted in 'broad brush strokes,' to a process which requires pre-specification of design and procedure. Thus, while the ethical principles and practices outlined in my proposal remained constant throughout the study, as described above, some of the investigative methods proposed were modified in the light of emergent thinking. In particular, the analytic methods used to interrogate the interview data were not envisaged at the time of submitting the proposal for ethical review.

3.5 Study population and sample; study site and recruitment

3.5.1 Study population

The study population comprised men and women aged 75 and older, resident in the North West of England, who had been diagnosed with one of four common cancers: breast, colorectal, lung or prostate. The age group 75 years and over was chosen because, although the population defined as aged 65-100+ is heterogeneous, the incidence of age-related physiological changes is reported to increase sharply between the ages of 70 and 75 (Gianni et al 2001). This means that a cut off of 75 years is likely to reflect more fully the complex intersections of cancer, comorbidity and old age (Thomé et al, 2003) than a cut off of 65 years, the conventional beginning of 'old age' throughout most of the 20th century in western industrialised societies. The four common cancers were chosen on the advice of senior oncology staff at the research site. My initial plan had been to follow Thomé et al (2003; 2004) and recruit widely and openly from among the target population, irrespective of cancer site. I accepted the clinicians' advice, choosing to regard it as at least a useful 'limiting and distributing device' (Kitwood, 1980; Hughes, 1993) which would facilitate recruitment.

3.5.2 Study sample

Factors which influence decisions about sampling size in flexible designs/qualitative research include (Morse 2000; Robson 2002): i) the nature of the topic (fewer informants are needed if it is obvious and clear; conversely more informants are necessary if the topic is challenging and difficult to grasp); ii) the quality of the data (fewer informants are needed if data are 'on target' and are 'rich and experiential'); and iii) the study design and methods (more data are acquired per participant with repeat interviews so fewer informants are needed; semi-structured interviews yield fewer data per person than in-depth interviews so more informants are needed). Morse (1994) recommends approximately 30-50 *interviews* (note, not informants) for ethnographic and grounded theory studies.

Taking account of the above recommendations, and placing them in the context of a biographical/narrative approach based on in-depth interviews which are likely to yield a lot of data, it was proposed to recruit up to 40 informants to the study, ideally 10 from each of the four cancer groups targeted. Inclusion criteria comprised: i) men or women aged 75 or older; ii) diagnosed with one of four targeted cancers: breast, colorectal, lung or prostate; iii) be well enough to take part in at least one interview, in English and lasting approximately 1-2 hours in length or otherwise provide relevant data (eg diary/journal).

As the study plan unfolded I decided to reduce the number of planned recruits from forty to twenty. In the time available to conduct the study it was deemed impractical to attempt to interview forty people. In addition, it was thought acceptable by my doctoral research advisors to reduce the number of recruits for empirical study in light of the extensive work already conducted as part of my doctoral studies in the form of a qualitative systematic review, forming the first part of this thesis and published in a peer reviewed journal (Hughes et al 2009, included at Appendix 5, p. 260).

3.5.3 Study site and recruitment procedure

The study was based at a regional Cancer Centre, and supported by consultant oncologists, the Lead Cancer Nurse and the Research and Development Directorate. The Lancashire and South Cumbria Cancer Research Network team also supported the study and facilitated initial access to clinicians.

3.5.4 Recruitment procedure

I identified eligible patients from oncology clinic lists with the assistance of administrative staff. I attended relevant clinics and drew the attention of consultants or specialist registrars to the patients I wished to recruit. Clinicians introduced the research to patients during the course of a routine consultation, supplying them with a single sheet of A4, written by me and including my photograph, which explained the study in outline (included at Appendix 3, p. 257). If patients were agreeable I then spent a few minutes with them before they left the clinic, explaining the study in more detail and giving them the opportunity to ask questions. With their agreement, I gave them a longer written Patient Information Sheet (see Appendix 2, p. 253) and invited them to think about participation in the study, discussing with family and friends if they wished, before making a decision. We agreed that I would contact them by telephone, after at least 48 hours had elapsed, to discuss any further questions and record their decision about participation.

In eleven clinic visits during the period April 2008-January 2009 thirty eligible patients were invited to talk to me about the research. It is important to remember that the first contact was made by clinic staff (consultant or specialist registrar oncologist) so that patients would have the opportunity to decline to see me, if they so wished.¹⁰ Twenty six patients agreed to see me.

¹⁰ Based on the assumption that reluctant participants would feel more comfortable saying 'no' to a clinician they already knew rather than to a researcher they had not met before. On reflection, I'm not convinced there is any evidence for this assumption. I had no control over the

Four patients declined, though one of these agreed to take the more detailed Patient Information Sheet and gave permission for me to phone her at home. She subsequently declined to take part in the study, confessing that she had not even read the Information Sheet.

Of the twenty six people with whom I discussed the study in outline while they were in the outpatient clinic six people subsequently declined, or were unable, to take part in the study. One man with prostate cancer declined because he was newly diagnosed and 'still in shock.' He indicated that he might write something for me (see Research Protocol, Appendix 1, p.237) but did not contact me again and it may be surmised that, out of politeness, he did not want simply to refuse all participation. Another man with prostate cancer agreed that I could phone to discuss participation but on each of two occasions was too unwell even to have a conversation with me. Another man with prostate cancer, the oldest potential recruit at age 87, agreed to take part and arranged an interview date but was subsequently admitted to hospital urgently with cardiac problems. One woman with breast cancer agreed to talk to me in more detail about the study but declined to take part as, when I telephoned, her husband had just been admitted to hospital with serious illness. One man with lung cancer (and other chronic health problems) agreed to take part in the study and arranged an interview date which he postponed on two separate occasions owing to his own and his wife's illness. Finally, one man who turned out to have had anal cancer, not colon cancer as I initially thought, regarded himself as cured and declined to take part on the grounds that he felt he would have little to say.

Three deviations from the recruitment protocol arose from practical and ethical decisions made in the field. One patient was recruited who fell slightly outside the lower age range for inclusion (she was 74 years old at the time of recruitment). This was a pragmatic decision the reason for which is explained in my contemporaneous field notes:

Clinic visit November 17th 2008

manner in which the invitation to meet me was presented by clinicians and, for all I know, it could have been presented in a way which made refusal unlikely.

3 eligible male patients (age 76, 79, 78). One female aged 74. Very tempted to be flexible on age criterion today because I have so few women (only one so far) and because if all 4 agree today that is my colorectal cohort achieved and won't need to come again. Since it's best part of a day each visit that is an important consideration.

The second deviation was that I accidentally recruited a man who did not, strictly speaking, meet the inclusion criterion of having one of the four major cancers. I had assumed that all the patients attending the clinic on November 10th 2008 were patients with colorectal cancer. Hence, the discussions with clinic staff about their eligibility focused on the age criterion rather than the cancer criterion. Because I had decided in principle not to look at patients' notes before meeting them (to avoid creating preconceptions about them) I did not realise until after recruiting him to the study that this person, whom I thought had colorectal cancer, did, in fact, have a gastro-intestinal stromal tumour. Because the cancer was of the gastrointestinal tract I decided to retain him in the study.

The third deviation was that the spouse of one participant specifically requested, at the recruitment meeting, that she be interviewed as well because she wanted her experience as a carer to be heard and, she said, in his presence, that her husband was not 'gifted with words.' Although this deviated from the study protocol I felt it to be within the spirit of the moral purpose of the research and agreed to interview her separately from her husband, though, again, in his presence.

3.5.5 The study participants

Twenty people, thirteen men and seven women, agreed to take part in the study and were interviewed in their homes. Details of the interview method are reported in Chapter 4. The participants' demographic and biographic details are summarised in Table 3.1 (p.91). One quarter of the participants (5 people) was aged over 80, the oldest (male) being 87 and the youngest (female) 74. Twelve participants were married (two for the second time: one following bereavement, the other divorce); nine were widowed and one (in addition to the remarried

divorcee) was divorced. Eight of the participants were living alone at the time of interview, eleven with a spouse or partner and one with an adult child. Of the thirteen men interviewed five had been widowed (one of them twice); of the seven women participants four had been widowed. One man and one woman had been divorced. Five men were living alone at the time of interview and three women.

None of the participants was in paid work but one man (Don Gorman) was actively pursuing creative and business interests at the age of 84, undeterred by knowledge of his rapidly advancing prostate cancer. Several others were actively occupied in a variety of ways: for example, with hobbies (Henry Jameson, Reggie Heptonstall) or with family concerns (Maria Preston, Reggie Heptonstall). A brief biographical sketch of each participant, drawn from what they said about themselves during the interview, concludes this chapter. A summary of their disease characteristics (age at diagnosis, treatments undergone, reported side-effects and comorbidities, and other experiences of cancer) is presented in Table 3.2 (p. 94).

3.5.6 Brief Biographies (all names are pseudonyms, listed in alphabetical order by first name)

Alec Smithson (m. Lung Cancer, interviewed April 23rd 2008)

Alec was born in 1930. He worked in the stores department of a local factory. He has two daughters and a son, all living nearby and giving him a lot of help and support. He also has close friends with whom he still manages to socialise. Alec's lung cancer was discovered following a persistent chest infection. He has had chemotherapy, from which he suffered some transitory side-effects. At the time of interview, he felt that his osteoarthritic knees (he was a football player as a younger man) impede his daily life more than his cancer. Alec's wife died from cancer during the 12 months preceding our interview.

Anne Fitzgerald (f. Breast Cancer, interviewed February 25th 2009).

Anne was born in N Ireland, in 1930, one of eight children. She had rheumatic fever as a teenager, which affected all aspects of her life. She had heart

surgery in 1953 (which ‘changed her life’) and again in 1993. Anne married and came to England in 1957 and worked (lifelong) with her husband in their taxi business. They had two children, with one of whom Anne has lived since the death of her husband in 1995. She had a stroke while pregnant with her second daughter, and still has a dense right hemiplegia. She feels that if she’d had physiotherapy at the time it might have helped her to recover function. Anne detected a breast lump and was diagnosed with breast cancer in 2006. The cancer was treated initially with medication then with surgery, which she resisted at first as she felt she’d had enough operations, and radiotherapy. Anne feels very satisfied with her treatment and has no after effects. She is glad, though, not to have needed chemotherapy. She takes Tamoxifen daily along with other medications for blood clotting, hypertension and osteoporosis.

Barbara Gormley (f. Breast Cancer, interviewed January 13th 2009).

Barbara was born in 1928, one of seven children. For reasons she still doesn’t understand, she spent about 5 years of her childhood living with nuns in what she called a ‘private orphanage’, though both her parents were alive. She left school at fourteen to work, first in a bank then, during the war, weaving in a cotton mill. She then left home to work as a nanny, followed by factory jobs in the shoe manufacturing and electrical industries. Barbara attributes her delay in marrying (at age 37) to her youthful passion for dancing. She had two children (deliberately unwilling to produce the large families typical of her Irish relatives) and continued to work in her own small businesses (chip shop followed by newsagent). Barbara’s husband died from oesophageal cancer in 1986. Her son and daughter live nearby. She sees them regularly enough to do their washing and to help with childcare. Over the years Barbara has also fostered seven children. In the last 4 or 5 years she has been treated for breast cancer (surgery and radiotherapy) a kidney problem (surgery) and bladder cancer (chemotherapy). Her attitude to these illnesses is that ‘life must go on, and you just bounce back’. She is very satisfied with all her treatment in the NHS and is eager to get back to voluntary work in a local charity shop.

Bernard Harley (m. Prostate Cancer, interviewed May 1st 2008)

Bernard was born in 1929. He worked as local government officer. He and his wife have lived in the house they currently occupy for 40 years. They have no children, but are 'honorary grandparents' to their General Practitioner's two boys. Bernard's prostate cancer started early 2000s with classic symptoms of an enlarged prostate gland which he found increasingly troublesome. Specialists recommended medical treatment and 'watchful waiting' for several years, which he found to be unsatisfactory. He has recently had surgery and is hopeful of the complete remission of his symptoms. His wife has been treated for breast cancer.

Bill Maugham (m. Lung Cancer, interviewed June 5th 2008. Died November 2008).

Bill was born in Blackburn in 1933. He left school at 15 and became an apprentice plumber. He spent some time in the army then returned to plumbing. He worked for many years as a plumber, including a period of self-employment which he did not care for, and finished his working life in general maintenance in his local general hospital. He is married with one daughter who lives nearby. He began to smoke when he was in the army and smoked for many years, but had stopped before the symptoms of lung cancer began. He was shocked to hear that he had lung cancer and was disheartened that nobody seemed to want to talk about illness when he went for radiotherapy treatment.

Clive Daws (m. Prostate Cancer, interviewed April 17th 2008)

Clive was born in Wales in 1924. His dad was a miner but didn't want his sons to follow him and all three boys worked in the aerospace industry. With the help of his older sister Clive saved enough money to buy a house when he got married to Alice. They have two daughters and in 1999 they moved to Lancashire to be near one of their daughters and their grandchildren. Clive discovered he had prostate cancer after mentioning his symptoms to a nurse when he was in hospital having surgery to his hip. He had radiotherapy and now fears his disease is advancing as the oncologist wants to start giving him injections.

Daniel Mattheson (m. Lung Cancer, interviewed May 7th 2008. Died January 2009)

Daniel was born in 1930. He worked in horticulture for much of his life, and ended his career as groundsman at his local city football club. He lived for 20 years with diabetes and was proud of the systematic way he managed his life to maintain health. He took the same approach to life with lung cancer. The side-effects of his chemotherapy treatment gradually abated though he still could not tackle the heavier work he would like to do in his garden. His sons-in-law helped with this. Daniel and his wife were planning a holiday in Austria at the time of interview.

Don Gorman (m. Prostate Cancer, interviewed May 30th 2008)

Don was born in Scotland in 1924. He intended to become an architect but WW2 intervened and he became an engineer instead. He travelled frequently to the USA and Russia, even meeting President Krushchev. He lived and worked in Ireland for a period, where one of his sons still lives. He has had surgery, radiotherapy and hormone treatment for prostate cancer. He knows that his cancer is advancing but he is unworried and concentrating on developing a new business for the creation and sale of 'Celtic Heritage' designs, for which he has taught himself to use some new computer software.

Doris Fletcher (f. Breast Cancer, interviewed January 8th 2009).

Doris was born in 1932 in the small Lancashire village where she still lives. She had a very happy childhood living with her parents and three sisters. She left school at 14 and worked in an office until she married at 21. She had a son and a daughter who have both married and divorced and who still live in nearby villages. Her children's marital separations followed quickly on the death of her own husband from prostate cancer in 1996 after 43 years of marriage. Doris talks repeatedly about having had a happy life and that she has no regrets apart from not disclosing sooner that she had signs of breast cancer, which she kept to herself for about 18 months before eventually visiting the GP in Dec 2007. She has had hormone treatment and surgery and is satisfied that her cancer is under control. She is also very satisfied with all the treatment she has received in the NHS. Her attitude to problems is generally to face up to them and accept them and this is now how she approaches having cancer.

Henry Jameson (f. Colorectal Cancer, interviewed Nov 24th 2008)

Henry was born in 1932, in a Lancashire village close to where he still lives. He left school at 14 and worked in a range of agricultural jobs. Henry married in 1960 and together he and his wife had three children. Henry's wife died in 1988 from lung cancer. He enjoyed close relationships with several women over subsequent years but did not want to remarry. He lives alone but has many friends and an active life. For a number of years Henry had bowel symptoms and didn't 'feel right,' latterly noticing blood which he assumed was 'piles'. At Christmas 2007 he suddenly started to bleed copiously and had to be rushed to hospital. Initially Henry was told he had a burst ulcer but after further investigations was given a diagnosis of colorectal cancer. He was shocked at this but fairly quickly came to terms with it and developed a very positive and determined attitude towards recovery. He underwent both radiotherapy and chemotherapy to shrink the tumour and then had to have surgery, leaving him with a permanent colostomy. Henry's stories about his illness, and his life, are underpinned by his great appreciation of all the help and support he received from his family, friends, neighbours, doctors and nurses.

Jack Flowers (m. Colorectal Cancer, interviewed December 1st 2008)

Jack was born in 1929, in a large Lancashire town. He left school at 14, had a few different jobs and then did National Service in the army, where he was stationed in Germany. He didn't care much for military life. On discharge from the army in 1956 he worked as a postman for a short time before getting a semi-skilled factory job as a turner, making engine components. At that time he moved, with his wife, to the house they still live in, where they raised two sons. Jack worked at this job until 1986, when he was made redundant. Subsequently, he worked until retiring aged 65 in a local hospital, again delivering the post. Until retiring Jack had always been fit, but since then has undergone numerous operations. Colorectal cancer came as a surprise, without any overt warning symptoms, in 2007. The cancer was treated with surgery, leaving Jack with a colostomy, which he really didn't want, and chemotherapy, which left him feeling nauseous and tired but which he described as essentially 'no problem.' The cancer has progressed to his liver and, in consultation with his physician, he has decided not to have more surgery, but is continuing with chemotherapy.

Jack's attitude to having cancer is fatalistic. 'There's nothing you can do about it,' he says, 'you just have to get on with life'.

James Hitch (m. Gastro-intestinal Cancer, interviewed Nov 11th 2008)

James was born in 1933, in Northern Ireland but moved to Lancashire with his parents at the age of 3. He left school at 14 and began a seven year engineering apprenticeship. He then spent two years in the army, which he broadly enjoyed, before returning to engineering. Jim worked for two large engineering enterprises in local factories for a total of 27 years, before taking early retirement at the age of 57 after his wife died from breast cancer. He now lives with a new partner whom he describes as 'a stalwart.' Jim experienced pain and swelling in his stomach over a 2-3 year period before finally receiving a cancer diagnosis in 2006. He underwent surgery and two extended periods of drug treatment, the second of which was ongoing at the time of interview. Jim spoke of his distress at the diagnosis but does not dwell on having cancer and is optimistic that treatment will be successful.

Jean Innes (f. Lung Cancer, interviewed May 22nd 2008).

Jean was born in 1929, and raised on a farm. She became familiar with the world of medical and surgical treatment from a young age having a cleft lip and palate corrected in her infancy. She worked in a munitions factory towards the end of WW2 and in a mill for the next for 30 years. She divorced from her first husband, who beat her, when their two daughters grew up. One of her daughters died a violent death aged 28. Jean grieves for her but does not feel bitter about her death. She is now married to Arthur, a childhood friend. She has suffered from a rare non-malignant tumour affecting her legs and her eyes and, more recently, has developed lung cancer. She has had radiotherapy and is enrolled in a clinical trial investigating the benefit of the drug Tarceva in the treatment of lung cancer.

John Raven (m. Prostate Cancer, interviewed June 3rd 2008)

John was born in Essex in 1931. When he left school he joined the merchant navy and worked his way up the ranks to command of a ship. He left the navy aged 26 and joined a general management trainee scheme in industry. He gained a series of promotions over the years, taking him to various towns and cities in the United Kingdom as a factory manager. He took up the opportunity of private health screening offered by his company and discovered, at the age of 65 that he had prostate cancer, a disease which killed his father and his younger brother. He underwent a radical prostatectomy which left him with permanent urinary incontinence, made worse by radiotherapy seven years later. All his days are dominated by the need to manage this so as to avoid discomfort and embarrassment.

Margaret Fletchley (f. Colorectal Cancer, interviewed November 26th 2008)
Margaret was the youngest participant, born in 1934. She enjoyed a life free from serious illness until she developed colorectal cancer, though cancer was present in her family. One of her sisters died from bowel cancer and her mother from cancer of the oesophagus. Margaret started work at the age of 15, in a mill office, and worked full time until her first son was born when she was 23. From then on she combined motherhood and part-time work. Since retiring she and her husband have continued to enjoy caravanning, and Margaret also likes to knit clothes which she offers to charity shops for sale. She began to experience pains in her stomach which she endured for some time before investigations confirmed a diagnosis of colorectal cancer. The tumour was surgically removed and, at the time of interview, Margaret was continuing treatment with chemotherapy. Her attitude to having cancer is fatalistic. 'It's there,' she says, 'you've got to accept it.'

Maria Preston (f. Breast Cancer, interviewed February 17th 2009).
Maria was born in 1928 in the small Lancashire town where she still lives. She was one of five children. She worked in a factory when she left school until she married at 19. She had four children, one of whom died from a brain tumour aged 28. Maria worked part-time as a cleaner and supervisor in a local hotel and leisure complex and as a school dinner lady. Her husband was a long-distance lorry driver and died from a heart attack in 1994. Maria recorded in her diary

that the year 2007 was ‘a bad year for me,’ the year in which she got breast cancer. She attributes the start of her cancer to the stress caused by caring for one of her grandsons who appears to have a mental illness. Maria’s breast cancer was treated with surgery and radiotherapy. She has a residual lymphoedema and is often fatigued, but still likes to get out of the house to shop and to visit her dwindling number of friends and her three sisters and brother, who all live nearby.

Michael McArthur (m. Prostate Cancer, interviewed June 18th 2008)

Michael was born in Lancashire in 1933. His childhood was marked by several periods living away from his family, in an orphanage and in an approved school. He left school at 15. He joined the army aged 17 and served in Germany. He enjoyed life in the army. He subsequently worked as a labourer and in the parts department at British Aerospace. He had three children, one of whom has died. His wife died from cancer about nine years ago. Since then he keeps his promise to her to tend their garden, which he is now finding tiring. His prostate cancer started several years ago and eventually he had a prostatectomy. The oncologist wants him now to have radiotherapy but he is resisting this at present.

Pamela Gallagher (f. Breast Cancer, interviewed January 21st 2009).

Pamela was born in Dun Laoighaire, Republic of Ireland, in 1930. She was the second eldest of eight children and spent her late adolescence as a primary caregiver to her younger siblings after leaving school at 14. At 16 she went to work, at first in a gift shop, then in the Irish Sweep and finally, until marriage, in a toffee factory. Pamela married in 1955 and moved to Lancashire in 1956. She had five children, two of whom died aged 16 and 21. Her three remaining children live nearby and are, she says, ‘very good to us.’ Pamela found a lump, accidentally, under her arm but didn’t mention it to anyone for about a year before visiting the GP and receiving a diagnosis of breast cancer. She was referred quickly to hospital and treated with surgery and radiotherapy. She was highly satisfied with all her treatment and care in hospital but a little disappointed at the lack of follow-up when she went home.

Reginald Heptonstall ('Reggie') (m. Lung Cancer, interviewed Oct 31st 2008. Died April 2009).

Reggie is the eldest participant in the study at the age of 87. He was born and raised in Manchester. He was a soldier in WW2 and was injured at Monte Casino. He enjoyed a varied working life. His adult years were filled with illness and injury of various kinds (he had eighteen operations). He had throat cancer in his early 80s, followed by the onset of lung cancer at age 82. He had a complicated family life and was divorced from his wife, though they were still friendly. Reggie was devoted to his family, his six children and all his grandchildren and great-grandchildren. He had an optimistic nature and did not dwell on his cancer. Since his treatment for lung cancer he had taught himself to draw and paint.

Richard Holmes (m. Colorectal Cancer, interviewed December 3rd 2008)

Richard was born in 1929, in the part of Lancashire where he still lives. He attended grammar school during the war years, but was little affected by the war since his father had died when Richard was nine and his elder brother was employed in a reserved occupation. He entered an apprenticeship in engineering when he left school at the age of 17. He progressed to work in the drawing office, interrupted by two years National Service in the army during which he worked on vehicle maintenance. He eventually became chief draughtsman and worked in the same firm till retiring at the age of 65. During retirement he has maintained his interest in engineering and in vehicles, building, over the years, three kit-cars for his son. After a lifetime without serious illness, symptoms of bowel cancer appeared suddenly in mid-2008. After initial brief delay in diagnosis, attributed by Richard to inexperience in the hospital doctors who first examined him, a consultant surgeon recommended the insertion of a stent, which immediately relieved his symptoms, followed by chemotherapy. He is hopeful that the treatment will 'buy him a few more years.'

3.6 Summary

In this chapter I have explored some conceptual and practical matters informing the design of a narrative study. I have given a detailed account of the ethical principles and practice governing my approach to interviews with potentially vulnerable participants on a sensitive subject. I have explained the method of sampling and the recruitment procedures employed and have introduced each of the study participants. In the next chapter I report in detail the methods used to generate, analyse and interpret the narrative data sought from these participants in relation to their life with cancer.

Table 3.1 ‘Cancer Stories’ Demographic characteristics (details derived from participants’ own narratives. No questions were asked directed at seeking this information).

Name (pseudonym)	Age	Gender	Ethnicity	Marital status	Living with	Other family	Occupation/s
Alec Smithson	78	M	W	W	Alone	2 daughters/1 son/grandchildren	Factory labour
Anne Fitzgerald	79	F	W	W	Daughter	2 daughters 4 grandchildren 2 siblings from 5 still living	Telephone bookings husband’s taxi firm
Barbara Gormley	81	F	W	W	Alone	1 son, 1 daughter 7 foster children 2 grandchildren	Mill Childcare Chip shop Newsagents Church caretaker ‘lots of jobs’
Bernard Harley	79	M	W	M	Wife	No children-‘honorary’ grandchildren	Local Government Officer
Bill Maugham	75	M	W	M	Wife	1 daughter	Plumbing and general maintenance
Clive Daws	84	M	W	M	Wife	2 daughters/grandchildren	Factory labour

LIVING WITH CANCER IN OLD AGE:
A QUALITATIVE SYSTEMATIC REVIEW AND A NARRATIVE INQUIRY

Daniel Matheson	78	M	W	M	Wife	2 daughters/1 son 8 grandchildren	Horticultural nursery owner and manager; football club groundsman
Don Gorman	84	M	W	W	Alone	2 sons, granddaughter	Engineer
Doris Fletcher	76	F	W	W	Alone	1 son, 1 daughter ?3 grandchildren	Office (wages) pre-marriage Shop post-children
Henry Jameson	76	M	W	W	Alone	3 children 7 grandchildren	Agriculture Wagon driving Agriculture
Jack Flowers	78	F	W	M	Wife	2 sons 3 grandchildren	Motor industry (30 yrs) turner, making engine components Hospital post room
James Hitch	75	M	W	W	Partner	2 children 2 grandchildren + partner's 3	Armature winder Aircraft wiring + Off licence
Jean Innes	79	F	W	M	2 nd Husband	2 daughters (1 deceased) 5 siblings	Machine operator (textiles) Local Government
John Raven	77	M	W	M	Wife	2 daughters	Factory manager

LIVING WITH CANCER IN OLD AGE:
A QUALITATIVE SYSTEMATIC REVIEW AND A NARRATIVE INQUIRY

Margaret Fletchley	74	F	W	M	Husband	3 sons, 1 daughter, x grandchildren	Office work (mill) Housewife
Maria Preston	81	F	W	W	Alone	3 sons, 1 daughter (died)	Cleaner (supervisor) Dinner lady
Michael McArthur	75	M	W	W	Alone	1 son (deceased) 1 daughter/grandchildren	Building trade (labourer) and aerospace (parts)
Pamela Gallagher	79	F	W	M	Husband	4 sons (2 died), 1 daughter grandchildren 3 great grandchildren	Office Factory
Richard Holmes	79	M	W	M	Wife	1 son, 2 daughters	Engineer, chief draughtsman
Reggie Heptonstall	87	M	W	D	Alone	4 children 6 grandchildren 6 great grandchildren nephews nieces	Bus driver Sales rep Club steward Hospital porter

Table 3.2 ‘Cancer Stories’ Disease Characteristics (details derived from participants’ own narratives. No questions were asked directed at seeking this information).

Name (pseudonym)	Age at interview	Age at diagnosis	Cancer treatment/s	Treatment side-effects	Comorbid conditions	Family experiences cancer
Alec Smithson	78	?	Chemotherapy		Orthopaedic	Wife died lung cancer
Anne Fitzgerald	79	77	Hormone therapy Surgery Radiotherapy	None mentioned	Osteoporosis	None mentioned
Barbara Gormley	81	77 breast 80 bladder	Surgery Radiotherapy Surgery Chemotherapy	Anorexia	Kidney removal post breast cancer and pre subsequent bladder cancer	Husband died cancer of the oesphagus
Bernard Harley	78	72 ish	Prostatectomy	Transient incontinence	Rheumatoid and osteoarthritis	2 sisters died
Bill Maugham	75	73	Chemotherapy Radiotherapy	Stomach pains from radiotherapy	None mentioned	None mentioned
Clive Daws	84	?78 ish	Radiotherapy	Nausea Diarrhoea	Orthopaedic	None mentioned

LIVING WITH CANCER IN OLD AGE:
A QUALITATIVE SYSTEMATIC REVIEW AND A NARRATIVE INQUIRY

Daniel Mattheson	78	77	Chemotherapy	Loss of appetite and lack of energy	Diabetes Hypertension	None mentioned
Don Gorman	84	?	Radiotherapy	'nasty' but not specified	Coronary Heart Disease Diabetes	None mentioned
Doris Fletcher	76	74	Surgery Hormone therapy	None mentioned	None mentioned	Husband died prostate cancer Sister died ?bowel cancer
Henry Jameson	76	74	Surgery Radiotherapy Chemotherapy	Post op pain + sinus Genital swelling and soreness (RT) Nausea, fatigue, weakness	None mentioned	Wife died cancer 20 yrs Grandson kidney tumour @ 18/12 (survived now 11)
Jack Flowers	79	? 77	Surgery Chemotherapy	Nausea and fatigue	Lots of operations since retirement : knees, teeth	None ('never come into contact with anyone who had cancer')
James Hitch	75	73	Surgery chemotherapy	Post op pain;Tiredness;Mouth ulcers;Night cramps	None mentioned	Wife died cancer 20 yrs
Jean Innes	79	71 Or 76?	Radiotherapy	Sinusitis	Osteoarthritis hip	None mentioned

LIVING WITH CANCER IN OLD AGE:
A QUALITATIVE SYSTEMATIC REVIEW AND A NARRATIVE INQUIRY

			Chemotherapy	Skin infections		
John Raven	77	65	Radical Prostatectomy + Radiotherapy + hormone therapy	Permanent urinary incontinence and impotence	High cholesterol	Father and younger brother both died prostate cancer
Margaret Fletcher	74	?72 but not clear chronology in interview narrative	Surgery Chemotherapy	None	None mentioned	Mother died cancer oesophagus Sister died bowel cancer
Maria Preston	81	79	Lumpectomy and lymph nodes Radiotherapy	Fatigue after RT Lymphoedema	High cholesterol	Family members and friends
Michael McArthur	75	60 ish	Prostatectomy	Reported no effects got over it easily	None mentioned	Wife died ovarian cancer 9 years

LIVING WITH CANCER IN OLD AGE:
A QUALITATIVE SYSTEMATIC REVIEW AND A NARRATIVE INQUIRY

Pamela Gallagher	79	76	Surgery Radiotherapy	Fatigue	Asthma	Son, died aged 21 Mother's sister died cancer Dad died lung cancer Nephew lymphoma ('just got the all clear') Husband survived bowel cancer
Richard Holmes	79	?	Surgery Chemotherapy	Lethargy	Current haematuria suggesting prostatic disease	None mentioned
Reggie Heptonstall	87	82	Chemotherapy Radiotherapy	None mentioned	None mentioned	None mentioned

CHAPTER 4

‘CANCER STORIES’: DATA GENERATION AND ANALYSIS

4.1 INTRODUCTION

In this chapter I report and reflect on the methods chosen to generate, analyse and interpret original empirical data intended to answer the question, ‘What are the subjective experiences of living with cancer described by men and women aged 75 and older?’ I begin with some commentary on epistemological matters concerning qualitative research data before going on to a detailed account of the primary method of data generation used in the study, the Biographic-Narrative-Interpretive Method or ‘BNIM’ (Wengraf, 2008, 2001). I go on to describe and explain at length the methods used to transcribe the interview data and subject them to a two-stage narrative analysis based on the concept of the *illness trajectory* (Corbin & Strauss, 1988) and on a reading of participants’ illness narratives (‘cancer stories’) in the light of their life histories.

4.2 Method of data collection/generation

The phrase ‘data collection’ implies that data already exist, just waiting for a researcher to pick them up, by whatever means deemed to be most appropriate to the circumstances (interview, questionnaire, focus group). In reality, the kinds of data sought for qualitative research studies (experiences, ideas, opinions) rarely exist in a pre-formed state, independently of the circumstances which researchers create to collect them. As already noted, the interview situation itself contributes to the type of data that are produced (Silverman, 1997). The phrase ‘data generation’ more accurately describes this process of constructing, not merely reporting, data (Wolcott, 1994).

In order to generate data for this study I conducted narrative interviews with twenty men and women aged 75 and older, living in the north west of England, with one of four major cancers (see Chapter 3) and all treated at the same

Cancer Centre¹¹. Interviews took place in the participants' homes, by their choice, and lasted between 2 hours (longest) and 38 minutes (shortest). All but three of the interviews fell within the optimum length of around 90 minutes for a single interview in narrative research (Hermanowicz 2002; Seidman, 1995). Written consent to their participation in the study was obtained from each person at the time of interview. Interviews were audio-recorded, with permission, and field notes taken during the course of interview, supplemented by immediate post-interview debriefing notes (Wengraf, 2001).

My approach to narrative interviewing was informed by reading of cross-disciplinary methodological and theoretical literature in the fields of life history and narrative research (Atkinson, 1997; Bornat, 2002; Bruner, 1987, 1991; Bury, 1991; Clandinin and Connelly, 2000; Cole & Knowles, 2001; Elliot, 2005; Frank, 1995, 2000; Riley & Hawe, 2005; Roberts, 2002; Sparkes & Smith, 2005; Stanworth, 2004) and finally determined by discovery of the Biographical-Narrative Interview Method (BNIM) (Wengraf, 2008; 2001).

My reading of this method, and application of it in my first interviews, led me to conceptualise a narrative interview as one in which the informant is enabled to tell a story.¹² This sounds straightforward but it requires a very different approach from, say, a semi-structured interview using an interview schedule based on questions which are designed to elicit a type of information pre-specified by the researcher. The story or stories sought in narrative interviewing according to the BNIM method may be whole-life stories or they may be partial life stories, about a particular aspect of the participant's life relevant to the research topic. The interviewer asks the informant to tell the story and then listens to what is said. No interruptions are made nor guidance given, which would influence the direction of the story towards the interviewer's interests and perceptions; rather, the informant is encouraged, by attentive listening, to keep talking until they have no more to say. Apparent diversions which might

¹¹ Since the Calman-Hine Report (1995) cancer services in the NHS have been organised to provide specialist services by region in Cancer Centres, typically based in a large NHS Trust Hospital.

¹² In my use of the word 'story' I am following Riessman (2008) in not being over precise about the distinctions between 'narrative' and 'story' and Webster and Mertova (2007) in emphasising the importance of the 'connected unfolding that we call plot' (p.19) as a defining feature common to all stories.

seem to contain irrelevancies are tolerated because, like a meandering river which eventually comes back on course, the diversion can produce material that does turn out to be useful and that may not have been generated with a more purposeful attempt to stay on track by interviewer questioning.

4.2.1 Biographic-Narrative Interview Method

I decided to use the Biographic-Narrative Interview Method (BNIM) because it offered a useful combination of openness and structure. I will go on to describe technical details of the method and ways in which it was modified in use during the course of my interviews.

BNIM requires that the interviewer first invites the participant to tell the story of interest, in their own words and without interruption from the interviewer. This is known as ‘sub-session 1’ of the interview. Agreement is gained that the interviewer will take written notes (as well as audio recording) during sub-session 1 and that after the respondent has finished speaking, and following an interlude in which the interviewer formulates questions based on the written notes, the interview will continue with questions. This is known as ‘sub-session 2’.

The questions in sub-session 2 follow the sequence of topics in the order that the respondent has spoken of them, in order to maintain the ‘gestalt’ (ie wholeness) of the interview and to honour the participant’s disclosures: to ignore something they have told you is to disrespect them, potentially to alienate them (Wengraf, 2008). Questions in this sub-session are designed to deepen and enrich the stories told, not to satisfy the interviewer’s curiosity on related topics, even those of relevance to the research question. Such questions may be asked in a ‘sub-session 3’ of the interview which, typically, will take place on a separate occasion (otherwise the interview is likely to go on too long for most participants’ comfort) and may be conducted over the telephone. Questions in sub-session 3 may take the form of a semi-structured interview. Questions in sub-session 2 should be of a narrative kind, asking for more detail on ‘what happened?’ I found that a single ‘story-telling occasion’ (Frank, 2000) comprised of a sub-session 1 and 2 yielded sufficient data from each participant and that it

was not necessary (or practical) to conduct a sub-session 3 of any of the interviews.

The strengths of this interview method are that it enhances the possibility that participants will speak of what they want to say, not what they might think the interviewer wants to hear, and that the combination of structure and openness allows flexibility for in-depth exploration. A major limitation of the method in use is that, in my view, it is too tightly structured, and its prescriptiveness can undermine the advantages of an open style of interviewing.

4.2.2 Modifying the method in use

From the first interview I found that I wanted to introduce modification to the method. I call these modifications 'variants.' By 'variant' I mean a decision I made to do something other than that prescribed in the method.

Variant 1. The initial question, intended to stimulate the participant to tell a story or stories related to the research questions, is supposed to be carefully composed and asked precisely as written. Wengraf (2008), fond of acronyms, calls this a 'SQUIN'; that is, a 'Single Question aimed at Inducing Narrative.' I found this to be unworkable. Reading a question, even one you have composed yourself, is not the same as asking it; and speaking it as written, without variation, is difficult in the dynamics of a social interaction (Mishler, 1986). Typically, a pre-prepared SQUIN is quite a long question (see Box 4.1, p.113) and I found some people interrupting me, eager to begin talking, before I had finished asking the question, or appearing visibly anxious as though they were going to be asked to do something they felt unsure of. My variation was to explain, using the core material from the question, before the interview began what I would be asking and then, at the beginning of the recording, refer back to the question. There is variation across the interviews in my precise wording of this. Mishler and colleagues (1986) argued that this is unavoidable and that it is unrealistic to expect absolute consistency in the interactional dynamic of a comparatively naturalistic interview setting. The content, and form, of the SQUIN changed slightly over the course of the interviews to invite life history as well as illness narrative (see Box 4.1, p.113).

Variant 2. Wengraf recommends the use of a customised notepad for note-taking during sub-session 1. I found this to be too prescriptive and that concentrating on trying to use it diverted my listening attention away from the participant. I only used it on one or two occasions, replacing it with my preferred method of a small notebook with blank pages and landscape orientation which could be held and used more discreetly, leaving me freer to interact with the participant (eye contact, bodily gestures, para-verbal vocalisations) in ways which encouraged talk.

Variant 3. Wengraf recommends an interlude of several minutes in which the interviewer composes questions for sub-session 2 based on the notes taken in sub-session 1. He suggests separation from the participant by some means (inviting them to make a cup of tea; taking yourself to the bathroom). On the one occasion (first interview) that I tried this I could not use the tea making strategy as the participant was not very mobile and it seemed too ridiculous and artificial to take myself to the bathroom for the purpose of note-taking. Consequently, I remained seated and with the agreement of the participant spent several minutes (about five) looking through my notes and composing questions. A long silence between individuals in a face to face interaction is uncomfortable. Hence the participant, after an interval of a couple of minutes, began to make comments about the interview and his hopes that it would be of use. I found this distracting, because I had to make a verbal response while trying to think about my questions.

My variation in subsequent interviews was to compose questions more spontaneously, based on reference to my notes (variant 2). This allowed a flexibility and a freedom of exchange which enhanced the interpersonal qualities of the interview, making it **seem** more like a conversation (McCormack, 2000; 2004) putting the participant, in most cases, more at ease and more ready to talk.

The risk of this strategy was to damage the 'gestalt' of the interview. For example, sometimes I began sub-session 2 with a question which followed up a story that had closed, rather than opened, sub-session 1. In the BNIM method,

not only is the interviewer supposed to begin questions on the topic which the participant first spoke about, but the questions should be in a forward direction only. That is, you are not supposed to return to a topic that you have not asked about after a topic that you *have* asked about. I found this to be too rigid a prescription. On occasions where I began a sub-session 2 in the way described above, I found opportunities later in the interview to return to earlier stories, to encourage a deepening of the narrative, and thus maintain the gestalt of the interview.

Although I have been concerned throughout the study with the technical aspects of conducting narrative interviews I was also aware that the foundation of a successful interview is in the relationship forged with the interviewee. Life experience, maturity and social skills, as well as previous experience of conducting life history interviews, all played a significant part in helping me to establish and maintain a relationship of trust with the participants in the study, beginning at our first encounter in the outpatient clinic. It was this relationship which encouraged participants to talk to me in detail about their lives.

Using extracts from my field notes and reflective journal, Box 4.2 (p.115) shows the developments in my thinking about the BNIM interview method, focused on the use of the Single Question aimed at Inducing Narrative (SQUIN) over a formative three week period preparing for and conducting the first interviews. These extracts show the key transition made from focusing exclusively on eliciting stories of participants' experiences since receiving a cancer diagnosis to incorporating an additional interest in their life story/biography before getting cancer. This was a key transition because it had become apparent from the first interviews that participants responded differently to the, broadly, similar request to tell the story of their cancer. In the first interview (Clive Daws) the participant spontaneously recounted stories extensively from his life before cancer, feeling that he did not have much to say about his experience of cancer. The third interviewee, by contrast, (Bernard Harley) presented a detailed and documented medical history, with few references to his life. The second interview (Alec Smithson) fell somewhere between the others in offering a brief account of his illness, with incidental and occasional reference to aspects of his life before he got cancer.

Reflecting on these differences in the light of my continual puzzling over method (Box 4.2 p.115) it appeared to me that the goal of understanding the impact of cancer on older people's lives would be more likely met by explicitly seeking to generate data based on their wider life story. In subsequent interviews, therefore, I invited participants to tell as much or as little as they liked about their life story before they got cancer in addition to the details of their cancer experience. This freedom to choose the amount of detail disclosed, without any direct questioning, maintained the spirit of BNIM inquiry. The data generated in this way provide material which helps to contextualise the experience of cancer. Chapter 8, in particular, provides analysis and interpretation of the 'cancer stories' in the context of what participants told me of their life stories.

It should be remembered that these are not whole life stories but partial and selected accounts told on a single 'story-telling occasion' (Frank, 2000). Elicitation of whole life stories would be likely to take many hours of interviewing (impractical within the boundaries of this study) and even then would yield partial accounts as people inevitably select from what they remember on particular occasions and what they wish to reveal to particular hearers. My intention, rather, was to seek a partial account, knowingly, in order to provide a) social 'lubrication' for the interview situation and b) context for the illness narrative which was the primary focus of attention.

4.3 Analytic method

4.3.1 Preliminary analysis: Transcription

Transcribing audio-recorded interviews can be seen to lie on the borderline between data generation and data analysis. Turning speech into text is the final act in the production of the interview as 'data,' though what is produced is more than simply a written version of the oral event (Czarniawska, 2004 citing Ricouer on 'discourse' and the interview as a speech act). If transcription is performed by the interviewer, it is, at the same time, the first act of analysis and interpretation. Sensitised to the theoretical importance of transcription by Elliott (2005) and Riessman (2008) I decided to transcribe the interviews myself.

I did not commit myself to an analytic method beforehand but sensed the importance of immersing myself in listening to the interviews while transcribing them. The benefit of such immersion is to allow time for thinking about the data as you perform the task of transcribing them. The task was made technically easier by use of transcription software (Express Scribe) and although it was time consuming, I regarded the time spent as a valuable investment in a stage of preliminary data analysis.

I conducted two stages of transcription. In the first version, which I called the 'raw transcript,' I concentrated on making a verbatim recording of the whole interview, including paralinguistic utterances, and adding marginal commentary on the interview content, on body language and on extra-vocal sounds (eg one participant rubbed his hand continually on the arm of his chair, a sound which was clearly picked up by the recorder placed nearby). I made this transcript as soon as possible after the interview (usually within a day or two) and, preferably, before conducting the next interview (I achieved this in all but one case) so that my memory of the interaction was fresh.

In the second version, which I called the 'worked transcript,' I concentrated on constructing the interview as a written document, paying attention to the insertion of punctuation marks and paragraphs. The initial impulse for doing this was so that my supervisor could read a transcript. Having had experience of reading long transcripts of interviews which I had neither conducted nor heard, and which were rendered verbatim with no imposition of structure or grammar, I felt that it was important to make the transcript readable.

I also wanted the transcript to reflect the character and personality of the speaker. Consequently, I tried to represent speech patterns, rhythms, accents, idiosyncracies of grammar and punctuation, as faithfully as possible. I wanted the transcript to sound like the voice of the person I heard, as a way of representing their individuality. For example, many participants frequently used 'like,' as a qualifier or as a way of pausing to represent ongoing thought. Many dropped initial consonants or end vowels to blend the definite article with a vowel sound ('th'ospital; 'th'army'). Some words were regularly truncated ('wi' for 'with') and the possessive pronoun given as 'me' (sounds like 'mi' as in

'give') instead of 'my.' Plural participles were substituted for singular ('were' for 'was') and there were frequent glottal stops ('end o't' day').

McCormack (2000, 2004) makes the 'lens of language' a particular feature of her narrative analysis of conversations with a postgraduate student on the theme of leisure. She makes observations about the significance of her own language (diction) and of the implications of pauses in the informant's speech (signifying hesitations of thought). I stopped short of drawing such inferences from the particular ways of speaking recorded in the worked transcripts. But I continued to regard the faithful rendering of speech as a way of honouring the individuality of the participant (reflecting the moral purpose driving the research) and of providing a basis for analysis and interpretation of the data. My own positive attitude towards this practice was reinforced by enthusiastic responses from two critical readers (my supervisor and one member of my review panel) of one worked transcript who both felt that the method of transcription enhanced the reader's ability to engage with the content of the interview and to interact with the person as an individual.

Transcripts were created as analytic tools. They represent my rendering of the data generated in the interview and form the basis of my 'retelling it afterwards' (Bourdieu, 1993 p.61). Many qualitative researchers choose to return transcripts to participants (Lincoln & Guba, 1985; Riessman, 2008). There is a putative analytic purpose for doing this and a moral purpose. The putative analytic purpose is to request that the participant check the transcript for accuracy, so that the researcher can be sure that the data as recorded represent the data as given. I call this a 'putative analytic purpose' because I think, respectfully, that no serious analytic purpose is served by this strategy. On the contrary, returning transcripts can have the effect of distracting from the data. The transcript differs from the interview in being a form of written discourse rather than speech (Czarniawska, 2004 citing Ricoeur). Consequently, participants sometimes focus on their dissatisfaction with their speech as recorded, particularly where it deviates significantly from standard English, to the extent of requesting that the record of their speech is altered so that it sounds, for example, more grammatical (Hughes et al 2005).

In addition, participants may, when reflecting on the written record of their spontaneous speech, wish to exclude some of the content of the interview. To acknowledge the participant's ownership of the research data in this way is part of the moral reason for returning transcripts. It is, of course, the participant's right to make such requests. However, the researcher does not, I would argue, have a corresponding duty to create a situation in which some of the data may be removed.

I thought long and hard about whether to return transcripts to participants, having made the assumption that I would do so, based on my familiarity with literature on qualitative research methods and ethics. I decided that I would not return transcripts routinely, though would supply them if requested. The reason for this decision lies in the nature of the contract I had established with participants. Essentially, participants agreed to give me their stories on the condition that I would write something about them that would be helpful to other people in a similar situation (see Participant Information Sheet, Appendix 2, p.253). I agreed to feedback products from the research (ie completed pieces of work) but did not commit myself to return interim work. The Participant Information Sheet states that:

- You can have a copy of the recording to keep if you want one (implication: you have to ask)
- You can have a copy of the transcript and comment on it if you want to (implication: you have to ask)
- I will give you a copy of the final results and I may ask you to comment on preliminary findings (implication: commitment to send final product but permissive on pre-commentary).

The sole commitment in terms of initiating action is that I will send a copy of the final report (probably a summary of the research findings written for a lay readership). None of the participants asked for a copy of the interview transcript. One participant asked for a copy of the audio-recording of the interview, which I duly supplied on a CD (his preferred medium). One participant asked what I 'was going to do with all this' and I explained to her in outline the process of transcribing and analysing the interview and of writing up the research.

4.3.2 Substantive analysis 1: Seeking a narrative method

Narrative research is a family of methods (Riessman, 2008) and it is not always clear that there is an analytic process ready made (unlike Grounded Theory, for example) which can be applied. Narrative data are qualitative data and can be analysed in any of the ways that qualitative data are analysed; by applying coding frames of various kinds to generate themes and categories, which may form the basis of interpretation and/or theorising.

Or, they can be analysed narratively (Bingley et al. 2008). This means that the 'coding frame' is formed out of narrative features that are embedded in the telling of stories: for example; time, place, personal and social context (Clandinin & Connelly, 2000). Some analysts also pay particular attention to the form (language and structure) in which stories are told as well as, or instead of, their content (see Elliott, 2005 on Labov, Gee etc., Frost, 2009).

I found a narrative device to structure analysis of my interview data in the concept of the 'illness trajectory' (Corbin & Strauss, 1988). The illness trajectory consists of a temporal arc during which a particular series of events typically occurs (not as straightforwardly linear as represented here, obviously, but the general shape holds good):

- the first noticing of signs or symptoms (of cancer, in this case)
- subsequent 'health seeking behaviour' (ie telling somebody about it; going to the doctor)
- referral to specialists
- investigations
- diagnosis
- treatment
- situating self living with cancer beyond treatment

From repeated listening to the interviews, and the two-stage transcription of speech into text described above, I sensed that my data could be interrogated fruitfully using this device. Most of the participants told 'cancer stories' which could be seen to follow something like this trajectory (there was one notable

exception). The 'cancer stories' extracted from these interviews are responses to the basic request, phrased slightly differently among the interviews (Mishler, 1986), 'Tell me what happened'. The responses to this request were not always straightforwardly sequential. Participants started at different places in their life, some with birth (Bill), some with more recent events (Maria began with the death of her husband), one with the cancer story itself (Margaret). Two participants told stories structured by thought-association rather than by chronology (Jean and Margaret).

Sometimes I uncovered more detail and more chronology at a later point in the interview. So, the 'told cancer stories' which are the basis of this analysis are in some ways constructed by me from the data. They are all the participants' words but they are not all whole sequences which were clearly embedded in the interview just waiting for me to lift them out.

The findings reported in chapters 5-7 are based on these told cancer stories, contextualised and interpreted in the light of relevant literature and theory. I really wanted to be able to reproduce the cancer stories at length (see Bourdieu et al, 1993 and cf Grinyer, 2002 p.170) but, at more than 46 000 words, they are too lengthy. There are, though, two cancer stories which are short enough to be reproduced in full and one of them may be used as an example of how I used the concept of the illness trajectory as a structural device for analysing the interviews.

The story of Anne's cancer is given a title using a phrase from her own speech (see McCormack 2004; Bourdieu et al 1993). The transcript is organised, here, to draw attention to its structure as it relates to the illness trajectory. Note that in the interview and in the worked transcript all this material is sequential.

Well, you could have knocked me for six

[First signs/doctor and referral/investigations]

I noticed this lump one night when I was bathing myself
and I went to the doctor.

So he sent me to hospital.

And, of course, they done the tests, the biopsies and things.

[Diagnosis and reaction]

And then they said it was cancer.

Well, I was that...honestly, you could have knocked me for six.

[Treatment]

So, I told him I didn't want any more operations. I'd had enough.

So, he kept putting me on these tablets, different tablets, thinking it would help it. But it didn't.

So, to finish up, then, I had the operation.

That's a year past Christmas there. I was in over Christmas and the New Year.

[Situating self in a life with cancer]

So, thank God, I've felt alright since.

The only thing about...I've no balance for walking but that has nothing to do with that, you know.

The doctor done a good job, so he did, yeh, not so bad.

This narrator was brief and concise, but also comprehensive: all stages of the illness trajectory are reported, in outline. Other participants told longer, equally comprehensive but more detailed and expansive stories. In some it was less easy to trace the illness trajectory from the told story.

4.3.3 Substantive analysis 2: Reading the cancer stories in the context of participants' life histories

Chapter 8 draws on the wider life stories participants told. The findings in this chapter are based on an exploration of the narrative interview data using the analytic questions, 'What other stories is the person caught up in?' and 'What differences depend on being caught up in these stories?' (Frank, 2008). The analytic strategy here began with a decision that the outcome I wanted to achieve was a piece of writing which wove together description of the narrative data (what the participants said) with analysis and interpretation (what I did with the data and how I made particular meanings out of them), to provide both a discursive and explanatory account of what participants told me about their lives with cancer (Grbich, 1999).

The method I chose to do this was initially to focus on the structure of the life story as told by the participant. There was great variation in the detail and length of the life stories, so for this analytic purpose I chose an exemplar interview: one with a clear chronological structure and rich in biographical detail (Bill Maugham). The method was inspired by a combination of Labov & Waletzky's (1967) structural analysis and McCormack's (2004; 2000) approach to analysis of in-depth interview conversations. Essentially, this meant identifying relatively self-contained *episodic tales* (my coinage) within the story as a whole and labelling them with an *in vivo* title taken from the story (Bourdieu et al 1993; McCormack, 2004). This was a time consuming process and unworkable as a method to be applied to all twenty narrative interviews. However, the process provided what might be called a 'sensitising mechanism' which fostered close attention to all the interview data on repeated re-reading and re-listening. Four additional interviews (one from each cancer group) were analysed using the *episodic tales* approach with *in vivo* labelling, but without the micro-structural methods of Labov & Waletzky, in order to deepen familiarity with the interview content.

The overriding principle driving this method was an attempt to preserve a holistic rather than a categorical approach to the data (Riessman, 2008). This was a challenging and difficult process because, while I wanted to preserve a sense of the wholeness and uniqueness of each interview, at the same time, I wanted to make comparisons across interviews. For example, in relation to the analysis and interpretation of the life stories, told in the context of living with cancer, a dominant and cross-cutting theme of 'resilience' emerged, through a combination of familiarity with the data and a pre-existing orientation to the concept from the findings of my qualitative systemic review (Hughes et al 2009).

In addition, I interrogated the life story data from a more etic perspective using analytic questions suggested by Frank (2008): 'What other stories are people caught up in?' and 'What differences depend on being caught up in those stories?'. Exploring the data in the light of 'grand narratives' (Davey and Seale 2002) and the 'lens of culture' (McCormack, 2004) further helped to situate and interpret the private experiences reported by these participants in a broader social context.

4.4 Summary

In this chapter I explained in detail the methods of data generation and analysis applied to this narrative research. I argued that qualitative data are inevitably co-constructed in the interaction between interviewer and interviewee and that life-story data generated in this way should always be considered as partial, selective accounts. I gave a detailed account of the specific interview method chosen for this study, indicating some of its strengths and weaknesses and showing where I modified it in use. I proposed a four-stage analytic method comprising a preliminary stage of transcription, followed by two substantive phases based on the concept of the 'illness trajectory' and on ways of reading the participants' illness narratives in the light of their life histories. A final stage of analysis situated participants' personal stories in a broader social context. In the next four chapters I present the findings derived from the data using these analytic methods, interwoven with interpretive commentary which is informed by selective reading from relevant bodies of literature.

Box 4.1 The developing 'SQUIN'

1. Pre-prepared written SQUIN

“As you know, the reason I’ve asked to talk with you is that I’m researching what it’s like for older people when they have cancer. So, I’d like you to tell me please the story of how your cancer was discovered and how things have developed since then. I’d like you to tell me all the events and experiences that have been important to you personally. I’ll just listen to you for now, without interrupting; and I’ll jot down a few notes in case I want to ask you any questions when you’ve finished talking. Please take all the time you need and start at whatever point you want.”

2. SQUIN, as spoken, introducing first interview April 17th 2008 (italic represents participant interjections, square brackets contain explanatory comments written by me while transcribing)

“As I said, and as you know now, *yeh* the reason I’ve asked to talk to you today is because I’m interested in researching what it’s like *yeh* for older people who have cancer *yeh* so, we’ve already begun earlier with the beginning part of your story [the participant began to talk about first signs of cancer before I even asked a question] but *yeh* what I’m gonna do now is ask you to tell me, erm, what it’s been like for you *yeh* from the discovery of your condition and how things have developed since then...*yeh*...and I’m gonna try not to interrupt you ...*no, no*...just to let you talk, erm, and I’ll jot some things down while you’re talking in case I do then want to ask you some questions *no*...but start wherever you want and take as much time as you like”

3. SQUIN, as spoken, introducing 11th interview November 8th 2008 (italic represents interviewee speech or paralinguistic utterances; square brackets contain explanatory comments written by me while transcribing)

“So, as I said, erm, when we first met, what I’m interested in finding out about is what it’s like for older people *um* particularly people over 75 *um* when they’ve got cancer. So, what I’m going to ask you to do is to start off by telling me something about your life before you had cancer, going back as far as you like *uhuh*, erm, and then come on to the point where you found that you’d got

cancer and how things have been happening since then *right ok* is that ok? As I said [pre recording] I'm going to try not to interrupt you while you're talking *uhuh* though I'll give you some prompts if you feel you need them [responding to pre-recording comments voicing apprehension at uninterrupted story telling] and, er, and, er, I might just ask you to elaborate on a few things when you've finished what you've got to say. OK? *Yeh, ok.*"

4. SQUIN, as spoken, introducing 20th (final) interview Feb 29th 2009

"So, as we said, if you could start off by telling me something about your earlier life, in as much detail as you like, going back as far as you like and then come on to the part where you found you had cancer and what's happened since then."

Box 4.2 Extracts from ‘field texts’ (Clandinin & Connolly, 2000) regarding chosen method of narrative interviewing (BNIM) written in a formative 3 week period April-May 2008

April 10th 2008

The Single Question Inducing Narrative or ‘SQUIN’ (this method is acronym heavy) marks out the method as different from semi-structured or even depth interviewing. There is no interview schedule-you are there to elicit, hear and listen to the patient’s own story (of their life, their illness, their divorce-whatever) and you let them know that at the outset, inviting them to start at whatever point of the story they like, promising not to interrupt till they have finished but letting them know that you will take some notes (in addition to taping) so that you can follow up on some things later. (Precise wording of SQUIN will vary acc to purpose but should contain these as minimum).

April 14th 2008 field notes (recruitment visits to oncology clinic)

Thinking more over the w/end about my problems with the SQUIN. I woke Sun thinking that I need a sub-session 0, before sub session 1 and the SQUIN, in which I prepare the ground by getting to know the person a bit better by saying something like ‘tell me a bit about yourself’. Supplementaries might be needed to help with ‘what do you want to know’ type response eg where you were born, where you’ve lived, your family, work you’ve done...Also be ready to tell something about myself. That is, engage in some normal social relationship building-you can’t expect people to tell you straight off about their ‘story’. Having formed, fairly quickly, some kind of relationship you’ve probably got a better chance of the SQUIN then following more naturally and leading in/on to the story.

Note that this approach inevitably leads to co-construction of the interview (cf Wengraf’s claim at the recent CECo conference on narrative that co-construction is minimised in BNIM) because I then become a particular audience for the telling of the story-and the way I am perceived has been influenced by what they have already told me and what I have told them. And, irrespective of what we have *told* each other, we have *impressions* of each other.

Another thought was that sub session 1 and the SQUIN seem to me to depend on, for want of a better term, a 'competent narrator'; that is, all the person needs is the single question and the narrative, articulate, sequential, uninterrupted, will be induced and flow forth. There doesn't seem to be any room for the interviewer to *help* the narrator to tell their story, because that is deemed as introducing direction which will somehow warp the telling away from the narrator's interests and perception of relevance to what is perceived as the interviewer's interests. Fair enough, but if the narrator isn't giving you (much) story...Another thought yesterday was that this bit of BNIM is reminiscent for me of the traditional psychoanalyst's couch-the interviewer effacing themselves from relationship as they ask questions...I don't feel comfortable with it.

April 16th 2008

Rethinking my worries about the SQUIN and a need for a subsession zero. The reason not to worry so much about leaping into the SQUIN is that the interview is *framed*; firstly by any pre-interview explanations you give (which should be recorded-many people don't do this-fortunately I tend to record everything I can in as much detail as I can-could turn out to be a virtue here.) Secondly by brief reference right at the outset of the interview to what you are doing *as you know I'm interested in researching/finding out...what its like for older people when they get cancer.* So you do build up to the SQUIN rather than launch into it. The method does insist though on the faithful utterance of a pre-prepared SQUIN which you don't add to or miss anything out (principle: car engine everything needs to be in place and work in a prescribed sequence). Wengraf gives examples given of what happens if you (inadvertently) miss something out. For example, it is important to ask for both *events* (things that happened) and *experiences* (thoughts and feelings about what happened). And, acknowledging the likely feeling of awkwardness, novices are urged to READ the SQUIN from a pre-prepared script until you get used to it so you are sure not to miss or add anything. This feels too formal to me, though it may be a useful way of remembering that the interview is intended to be more than a conversation.

Wengraf insists also on no interruptions and no helping the person to tell their story in subsession 1 (can be anything from 5 to 155 minutes but should aim for 30-90) with anything other than narrative questions-otherwise it is not a

narrative interview but a semi-structured interview. And you are not to worry about the 'meander'- the story that is seemingly irrelevant to your CRQ (central research question) which you hold in the back of your mind but don't allow it to intervene-because the meander gets where it is going and, crucially, this is where you learn new information that may well turn out to be relevant and you wouldn't get if you pursued a straight line. This makes sense.

There do seem to be flights of over-prescription though, particularly in relation to notetaking for subsession 2. It doesn't seem enough to note key words and pick up on them in subsession 2. You have to use the BNIM notepad and look for 'magic words'-or is it 'magic formula'-on a brief glance frighteningly complicated and confusing. And you must pose your questions in search of PINs (Particular Incident Narratives) in the order the narrator referred to them in subsession 1 and you can't go back. Urged to pay particular attention to where the narrator chooses to start (in response to your SQUIN invitation to start anywhere) because that is often missed in the flurry of starting the interview, sometimes with bad consequences (example of interviewee starting with reference to his daughter which wasn't noted and no question asked-in a debrief the interviewee expressed bitterness that he hadn't been asked more about his daughter). The interviewer had entirely missed this on this occasion.

But if you realised part way through subsession 2 that you had missed something surely it would be ok to go back *you mentioned earlier....could I just take you back to that for a minute and ask if you have anything else you'd like to say about what happened then...*

April 18th 2008 (day after 1st interview)

Sense of discomfort growing through yesterday as I transcribed first interview-discomfort with my first performance of a BNIM interview but also with aspects of the method itself-specifically the reliance on a notepad, BNIM or other, to write while listening. I felt this was intrusive, took my eye contact and my attention away from listening-you can hear the notes pages rustling on the tape as I turned them, and the participant referred to my notetaking too. I didn't notice this so much at the time but listening to the tape and transcribing it's

clear that he is struggling to find stories to tell me and maybe my partial attention is partly responsible.

Hence I am still wondering, really, what a 'narrative interview' is and how to 'think narratively' (Clandinin & Connelly, 2000) about the material constructed in such an interview. Found myself looking up the quotation I noted from Annie Proulx's *Shipping News* (1993) as long ago as last summer:

Quoye, who spoke little himself, inspired talkers....His attentive posture, his flattering nods urged waterfalls of opinion, reminiscence, recollection, theorizing, guesstimating, exposition, synopsis and explication, juiced the life stories out of strangers. 1993 p9

This is my role model, this is what I need at the top of my BNIM notepad; simple, careful attentiveness not a medley of so-called 'magic words' and 'magic formulas'.

April 22nd 2008

Re my oscillating plans to introduce a pre-SQUIN or even abandon the SQUIN (and a ss 2 based on cue word written down in ss 1) because of a) feeling that informants will not be so readily enabled to tell a story as by simply getting them talking by conversational means and b) of my discomfort at uttering a completely prepared undeviated-from script, Wengraf writes, (page 27) that, like any interview, BNIM is 'artificial' compared to spontaneous conversation and, until you get used to it, BNIM will feel 'more artificial' than genres that you have practised' (oral history, for example, felt very natural).

'There are different strengths and weaknesses of collecting 'spontaneous talk and ordinary conversation' and of creating the 'artificial situation' of a carefully structured interview: complementary, neither are 'replacements' for the other.' And then there is more to justify adherence to the rules while learning this as a new method. OK, fair enough. And it does seem to have worked moderately well, given my novice limitations.

April 24th 2008

4 ½ hrs transcribing this morning has left me feeling dispirited because yesterday's interview (L1, the second interview I conducted) sounds and reads more like a conversation than a narrative interview. Told myself in my debriefing notes that I had 'juiced some life story' but I don't think I did really- did no more than keep him talking for longer than he might have otherwise-but to what (narrative) purpose I don't really know [and] the SQUIN is too long- especially if already given as pre-SQUIN which I think I need to do because I need to signpost to them what's going to happen....Rachel Stanworth's opening question comes to mind which was something like 'tell me what things have been like for you'; it's short and open so I could try, 'Tell me how it all started and what life has been like for you since then.'

I can say 'it all started' because it will already have been established (first meeting; info sheet; pre-SQUIN) that we are talking about their cancer but it also allows them to put in anything else. 'What life has been like for you' allows anything and everything too-maybe too much, so I may need narrative prompts, like:

Can you say any more about....

Can you remember anything particular about..

What happened after that....

Can you tell me about a specific time when....

May 12th 2008

I woke Sunday early thinking again about my sense that the way I am applying BNIM in my (4) interviews so far is not getting me the breadth and depth of life story that I think I want and wondering again whether to recast the approach, and the SQUIN, to say that what I am interested in is your life story? Then I remembered Bury's (2001) paper 'Illness Narratives: Fact or Fiction' and I had the thought that 'Yes, well, what I am after is a collection of illness narratives, in fact, more specifically cancer narratives,' but I feel, as a result of the first interview in which the participant spontaneously included elements of his biography, that I want to hear those illness narratives in the context of some life history.

CHAPTER 5

‘CANCER STORIES’: ANALYSIS AND INTERPRETATION OF FINDINGS (1) FIRST SIGNS OR SYMPTOMS OF CANCER AND MEDICAL CONSULTATIONS

5.1 INTRODUCTION

In this chapter, and the two following chapters, I report and interpret findings from the narrative study which relate to the diagnostic and treatment periods of the participants’ experiences of cancer. I attempt both a holistic and a categorical analysis (Riessman, 2008) by preserving as much intact narrative as possible, in the form of extensive quotations from interview transcripts, while at the same time presenting a thematic analysis in order to make some comparisons across cases. I present the findings with interpretive commentary in the light of relevant literature. I begin with analysis of the participants’ stories of the first signs or symptoms of cancer and their help-seeking behaviour. I go on to report their experiences of receiving and reacting to the diagnosis of cancer (Chapter 6) and conclude by reporting their experiences of treatment (Chapter 7).

Public health information about cancer has long stressed the importance of early detection as one way of maximising the chances of curing the disease. The underlying assumption is that if cancers are identified at an early stage of their development then treatment is likely to be more effective (DoH, 2007; Wilkins et al, 2008). The problem is that the uncontrolled and unregulated growth of cells which characterises the initiation and development of cancer (McAlister et al 1993) takes place beyond awareness of the sensing individual. By the time a person becomes aware of bodily change which may indicate cancer, significant windows of opportunity for effective treatment may have been lost. Consequently, developing the science of pre-symptomatic screening, along with health policies designed to provide screening services and to encourage their uptake, has been a major feature of cancer care and treatment over the last three decades. Most cancers, however, are detected as a result of symptomatic presentation

followed by medical investigations (Richards 2009). This was true for all but one of the participants in *Cancer Stories*.

The stories of cancer detection told by these participants may be grouped into four types of experience: i) those detected by screening; ii) cancers which had not produced symptoms (felt experiences) but which were detected by discovery of a 'sign;' that is, a physical change in the body; iii) cancers which showed themselves through the experience of symptoms, gradually worsening over time; and iv) cancers which suddenly and dramatically broke through into the person's life.

Table 5.1 (p. 141) summarises participants' signs or symptoms and first medical consultations. In sections 5.2-5.5 (below) I report these stories of the diagnostic pathway (Corner et al 2005) in some detail. I consider the stories in the context of delayed presentation (both patient and physician delay) and go on to link this to what I call the 'timeliness' of diagnosis.

5.2 Cancers detected by screening

It should be noted that routine screening for cancer is not offered to people in the UK who are aged 75 and older. John (age 76, prostate cancer) was the sole participant whose cancer was detected by pre-symptomatic screening which was provided, in his case, by a private health insurer. John enjoyed a successful career as a general manager in industry. He moved around the country as he gained promotions, and took the optimistic view that exposing his young family to different experiences would be good for their education. His skills were so well regarded by his company that when nearing retirement he was asked to take on a challenging assignment, managing two factories which were in difficulties, in a city he had worked in earlier in his career.

While still at work, around the age of 63, John took the opportunity of the private health insurance provided by his employer to have what he called a 'health check.' This showed that the level of PSA in his bloodstream was raised. PSA stands for 'prostate specific antigen' and a raised level of this substance in the blood stream may indicate the presence of prostate cancer.

It is not a clearly definitive test (no method of screening is) as the PSA level may be raised without the presence of cancer and there is controversy over its utility (Chapple et al. 2008). John's overall health, according to this report, was good except that

The lady GP, from Morecambe, can't remember her name now, very pleasant soul, said, 'your PSA is a bit... is a bit high, erm, by that I'm talking about 7.8 so not excessive but it's worth you going back and talking to your GP and perhaps pursuing it.'

John took this advice, continuing his story with an account of his conversation about this raised PSA with his own GP.

So, I went back and saw my GP, who was a gentleman probably in his 60s, and explained that, and showed him the report, who said, '7.9? Oh, I wouldn't worry about that,' he said. 'When it gets to 80 we'll start considering it.' So I said, 'Oh well, fair dos, but, you know, this lady GP had suggested I come and talk to you about it.' 'Well,' he said, 'if you want to do something about it and you've got private health then we'll pursue it if you like; it's up to you. I wouldn't do it through the health service with a PSA of that number.' So I said, 'Well, ok then, pursue it.' Um 'Do you want to go to Blackpool Vic or do you want to go and see a top man down in Manchester?' [laughs] 'I'll see the top man if you like!'

Having 'lost' his younger brother to prostate cancer in 2003 'because they didn't pick it up quick enough,' John affirms the value of pre-symptomatic screening when he observes that 'I have a lot to say for my health check'.

5.3 Cancers detected through discovery of a physical 'sign'

Barbara (age 81, breast cancer) was undergoing treatment for bladder cancer at the time of our conversation. I didn't know this when I arrived at her house, an old cottage in the lee of the ancient church which she tends, and felt some anxiety about the effectiveness of my recruitment strategy as I thought she had breast cancer. As she began to speak about her experiences it turned out that, in the last five years she has had breast cancer, a kidney removed and most recently, bladder cancer for which she was still receiving

treatment. She was active, babysitting for whole days her young grandson, and keen to get back to 'work' in her role as a volunteer in a local charity shop.

Barbara's breast cancer was detected by a mammogram, but in her mind she relates it to a serious car crash that she experienced around the same time.

I did have a car crash four or five years ago. I was coming...I was working in the charity shop and I was comin 'ome and I had a car crash and me car was wrote off and I had to go in hospital cos I was black [ie badly bruised] and I went in hospital. And, then, after, I'd to go for a mammogram. Now, with the car crash and the seat belt, the nipple had gone in. I mean, I might be wrong here but it was always at the back of me mind, with the crash, the nipple had gone in. I went for a mammogram and they said, 'Oh, the nipple's gone in.' And it's always been at the back of my mind, did I have cancer or not? But then I did have x-rays and I suppose...but always at the back of me mind I thought, 'Did I really have cancer?' But then, since then, I must have had it. I must have had cancer cos l...it's just 4 yea...Christmas.

The relationship of the mammogram to the car crash is not easy to establish in Barbara's reconstruction but it appears that her nipple, unknown to her, was inverted and that this was noticed by hospital staff when she was admitted for treatment following the car crash. Consequently, this potential sign of breast cancer was investigated while she was in hospital. In Barbara's mind, though, the inverted nipple was a result of pressure from the seat belt during the car crash. This lay belief is eventually superseded by her acknowledgement that she 'must have had cancer' before the crash.

Maria (age 81), Anne (age 79) and Doris (age 76) all discovered that they had breast cancer by noticing physical changes in one of their breasts. In medical terminology this would be described as a 'sign' of disease, rather than a 'symptom', which is a subjective experience of feeling unwell. Health promotion messages directed at women regarding breast health have changed over the years from recommendations for regular self-examination, in order to detect early signs of change, to a more generalised 'breast awareness' (Tu et

al 2006). In a national survey of 850 women aged 67-73 Linsell et al (2008) investigated women's knowledge of breast cancer symptoms and their confidence to detect breast changes. They found that 85% of the respondents were aware that a lump in the breast or axilla could be a symptom of breast cancer but that they were less knowledgeable about symptoms other than lumps, such as an inverted nipple (see Barbara's story above). Their knowledge of risk was overly optimistic, with 50% believing the lifetime risk of cancer is 1 in 100 (actually it is 1 in 9). And 75% were not aware that risk increases with age. A third of the sample were not confident about detecting change in their breasts. Both knowledge of symptoms and risk were strongly related to educational qualifications, with greater knowledge associated with more education.

The women in *Cancer Stories* noticed changes in their breast in what might be called an accidental fashion, rather than through conscious self-examination, but were knowledgeable about the potential significance of such a finding. For Anne it was simply that, 'I noticed this lump one night when I was bathing myself.' Maria discovered a change in her nipple when she was getting undressed. She wondered what was wrong with it, assumed it was ominous and associated it with the stress caused by her caring involvement in her grandson's chaotic lifestyle: 'Gosh, I'm not surprised, I'm not surprised it's...I've got all worked up over him, you see.'

Both Anne and Maria followed their brief description of finding the lump by reporting their prompt consultation with a doctor. Doris (76) and Pamela (79) both experienced some changes but delayed medical consultation (for eighteen and twelve months respectively). Neither of them reflected specifically on the potential impact on the development of their disease and the possible effects of the delay in presentation on the effectiveness of treatment (Richards, 2009). Wilkins et al (2008) note that awareness of symptoms does not in itself lead to help-seeking behaviour but that a certain level of concern about the symptom needs to be reached before a medical consultation is sought. Symptoms which most concern women include a lump in the breast (Macdonald et al 2004). Such concern may be a necessary but insufficient concern for help-seeking behaviour as both Doris and Pamela expressed both awareness and concern about their

symptoms (including pain in Pamela's case) but were prevented by fear from consulting their doctor. Nosarti et al (2000 p745) found that women who delayed presentation at a breast clinic specifically because they feared a cancer diagnosis had the highest median delay.

Doris began her account in a non-specific, disembodied way, without referring to any signs or symptoms, or even to her breast:

Well, it started off, I knew what it was, really, but I didn't want to face it you know [pause]. If I knew what I know now, I would have done it. But you can't... can you? So, I waited quite a while and then, in the end, I had to go and see to it. But I knew what it was, you know, you couldn't...I knew exactly what it was.

When asked, 'Could you tell me a little bit more about what was happening to you that made you suspect you had cancer?' Doris was a bit more specific:

Oh, well, I got the symptoms¹³. I had breast cancer and I got the symptoms. I got a little indent, you know, in me chest and I thought, you know, 'That's odd. That shouldn't be like that.' And I watched it. I watched it grow, you know. And I thought, 'There's something not right, here. It's not right,' you know, 'go tomorrer.' And I didn't [sheepishly], you know. And it got to the stage when I couldn't put up wi' it any longer and I went [to the doctor].

Later in the interview, after talking more about her life story, Doris comes back spontaneously to the beginning of the cancer story and her ignoring of the first signs, in the context of a general, evaluative comment about her life:

No, all in all I've had a good life. I don't regret anything whatsoever, nothing at all. Me only regret is I didn't go to the doctor's sooner. That's me one big regret. And I think if I'd have had some guidance, I would have gone but...

-What might have been different if you'd gone sooner?

¹³ The distinction made in this chapter between 'signs' and 'symptoms' is not commonly used by members of the public who generally refer to any indication of illness or disease as a 'symptom'. Foucault (1973, pp.90-95) traces the distinction to the eighteenth century and argues, elaborately but not persuasively, that the terms have become synonymous.

Don't know. I wouldn't have had that worry all that time would I? You know, I wouldn't have worried about it all that time, you know.

-How long was all that time?

Oh, about eighteen months. Something like that. Which was a long time, really. I think it was about that long. So, I wouldn't have had that, you know, you know. And when I look back I think, 'You idiot,' you know, 'you could have been like...' now it's like last year, I could have done that, say, two years ago, like I did last year, you know. But, er, anyway it hasn't to be and I'm here and that's it...

5.4 Cancers detected by the experience of symptoms, worsening over time

Pamela (79) differed from all the other women in the study with breast cancer in that she experienced pain under her arm, didn't think to look for a lump, but ignored the pain for twelve months before seeking medical advice.

I was sat just where you're sat. I knocked the newspaper down the side there bent over, I won't do it now, bent over like that [gestures] to pick it up and 'ohhhh!' [imitates gesture of pain under arm] the pain! And it lasted a while. I thought I'd touched....I'd done something, I'd pulled a muscle or something and then it would go away and it'd come back and I never thought of looking for a lump till, er, last Christmas, nineteen....where are we at, 06 and I didn't say anything over the Christmas. I waited till the New Year for it must have been twelve months beforehand that I'd hurt meself and I went to see me own doctor.

The four men whose prostate cancer was detected symptomatically (Clive, 84, Bernard 78, Michael, 75, and Don, 84) all showed the classic symptoms of prostatism, or an enlarged prostate gland: wanting more frequently to go to the toilet, hesitancy in starting to pass urine, with a faltering stream of urine which finishes with dribbling. In the same way that a lump in the breast may not be malignant, these symptoms of change in the urinary flow may indicate a benign growth in the prostate gland rather than a malignant one. None of the men in this study experienced painless bleeding while urinating, which may be a clearer sign of malignancy, though there are other causes of bleeding such as infection.

Clive had difficulty remembering the start of his symptoms and asked his wife to tell the story:

Clive was in hospital and it was after he had his hip done and he had thrombosis with both his hips and he mentioned to the nurse about going to the toilet. He had to go quite often [...] and she said to him, 'Do you go straight away, or do you sometimes stop and start again?' And she said, 'Well, perhaps you should see the doctor when you get home Mr. Daws'. And then he went to the doctor and the doctor referred him then to go to hospital to see [name] because he was spendin' a penny, stoppin', and then he'd go again, which is not, sort of, normal, you know. And he was havin' a bit of difficulty goin'. That was the start of it.

Bernard, by contrast, remembers the experience of beginning symptoms more clearly. He reports the first symptoms briefly but as the interview proceeds he goes into great detail, referring to written notes on his knee from time to time, especially when he wants to check a date.

Well, things started to go wrong, first of all, about 6 or 7 years ago. I started to require to dash off to the toilet at inconvenient times and, er, used to, fortunately, make it most times. Never more than a drop or two, but it still was inconvenient. And so I did go and see a consultant on my own, er, privately.

Michael seems to attribute his more frequent trips to the toilet to his beer drinking, though the way he tells the story leaves it unclear how long he has been having the symptoms:

I were on a racing trip in Leeds, some Labour club, and were drinking and I just said to this friend of mine, I said, 'There's summat wrong.' He said, 'What?' I said, 'I'm going to't toilet a lot,' I said. 'It must be t' beers, must be the water we're drinking.' And he said, kept on, he said, 'I think you'd better see your doctor.' So I went.¹⁴ I made an appointment, then he went through, he said, 'What do you think it is?' I said, 'I don't know', I said, 'I keep wanting to go to't toilet. I'm getting up a lot during't

¹⁴ This conforms to Smith et al's (2005) finding that help-seeking is prompted for some patients by the 'sanction' of friends or family.

*LIVING WITH CANCER IN OLD AGE:
A QUALITATIVE SYSTEMATIC REVIEW AND A NARRATIVE INQUIRY*

night,' I said, 'maybe three or four times.' And he said, 'Yeh. Does it dribble or drip?' I said, 'Yeh.' So he said, 'I'll make you an appointment.'

Don, after telling a long story of his life as an engineer, and needing a prompt to tell his 'cancer story', reports his first symptoms in few words, and makes no mention of a visit to the GP, moving straight to the story of his admission to hospital and a vivid account of his first investigative procedure:

And then, at the end of 2000, I was getting these terribly dry throats and the waterworks weren't too brilliant and, er, so I went in to hospital and this Indian guy [...], poked his finger up [vigorous gesture] and things like that and said, 'Oh, umm, you'll have to have a scan.'

Four of the men and one of the women in this study had lung cancer and, unsurprisingly, given the natural history of the disease and its lack of response to treatment relative to some other cancers, three of them died during the year or so that elapsed between conducting the interviews and beginning to write this account (DOH, 2005 p44).¹⁵ Corner et al (2005, 2006) conducted an interesting study of 22 men and women with lung cancer, designed to elicit information about the pathway to diagnosis. They sought to discover what symptoms people had (and when) which signalled, to them, a change in their health and what they did about it; that is, what was the 'trigger' event which took people to the GP and which led to investigations for and diagnosis of lung cancer?

Corner et al used a 'directed interview' which began with a semi-structured series of questions based on a (retrospective) time line starting with the question, 'What happened to me?' and tracking back over their memory of symptoms. A second part of the interview was structured and identical for all, asking more detailed questions about symptoms. An event line was constructed from these data and triangulated with GP and hospital records. Statistics were used to establish the measure of agreement between patients' memories and the written records. Interview data were also analysed thematically (Corner et al 2006) to gauge the patients' experience of symptoms. Thirty different symptoms were recorded and the most common (chest symptoms including

¹⁵ '...response rates for patients with lung cancer are always lowered in surveys of this sort because of higher levels of infirmity due to the presence of a number of co-existing conditions and significantly higher proportions of patient deaths after selection of the sample.'

cough and breathing changes) correspond to the symptoms reported (that is, the trigger symptoms) in three of the five participants with lung cancer in *Cancer Stories* (Alec, Reggie, Bill).

In Corner et al's study there were patient delays in the sense that perceived changes in health status were tolerated for up to a median of seven months before a trigger event (eg couldn't cope with a cough any longer, or an episode of haemoptysis) led to help-seeking behaviour. Physician delays, especially in the GP responses, do not seem to have been a feature of people's experience in Corner's study, despite patients presenting with symptoms which differ from those listed in guidance for GPs on suspected cancer. This finding is repeated in *Cancer Stories* 'where patients reported what sounded like prompt referral: Alec's GP wouldn't give a second course of antibiotics when symptoms persisted, but referred him to hospital; Reggie seems to have been referred quickly; both Bill and Daniel (and Marjorie, see below) commented on the speed of events.

Corner et al. (2005) conclude that lung cancer may not be, as it is commonly assumed, a 'silent' illness in which people do not experience any health changes until presenting with frank symptoms and advanced disease. The challenge, as indicated at the opening of this chapter, is to enable people to recognise early symptoms and to encourage them to act. It is a big challenge, given that no patients in Corner et al's study reported thinking that their symptoms presaged cancer, despite many being former smokers.

Alec (78) doesn't specify any symptoms but the brief story that leads up to his referral to hospital suggests that he had been visiting his GP with symptoms of a chest infection:

So, well... I, er, when I first went, I went to the doctors for some antibiotics. It was chest on me left hand side, and then, after that, I went for some more antibiotics and he, er, he says, 'No, I'd better send you to the chest clinic.'

Daniel (78) had organised his life for the previous twenty years around having diabetes. He had created a disciplined, daily programme to ensure that his diet, medication and exercise were all in balance. This long experience, he said,

helped him to cope with cancer. The first symptom of lung cancer was loss of appetite but he attributed this to cholesterol-lowering medication (statins) prescribed by his GP. When the appetite loss persisted, despite halving the dose of statins, he returned to the clinic:

I used to go and see the diabetic nurse about every three months for blood pressure checks, that sort of thing, and on that particular day I... she couldn't fathom it. And the GP whom I'm specified to be under, I don't think he was available on that particular day but there was another doctor upstairs, who I'd never met before. It was a lady doctor and... the level I used to go and see the nurse was on the bottom floor, I'd no stairs to climb. However, I went upstairs and I was out of breath *um* completely out of breath, perspiring profusely. So, when I went into her she, no further ado, got me on the couch and tested my chest and my back and on the phone referred me to the chest specialist.

Bill (75) had worked in plumbing and general maintenance since the age of 15, excluding his period of national military service. He had started to smoke when he was in the army, aged 17 or 18 and attributed his lifelong trouble with coughs, ('I bet I've had a session every year of a bad cough'), both to his smoking and to an episode of glandular fever during his national service ('I were never t' same after that'). When asked specifically about the symptoms which took him to the doctor before the diagnosis of lung cancer he said:

Well, I wasn't...I'd given up smoking then *had you?* Yeh, yeh, I hadn't , er, smoked, I hadn't smoked for 10 year now, or summat like that. I hadn't smoked, I'd given up smoking , then. But, what were I doin'? Were I 'avin a wash? And then I started, like, spitting blood, like, you know, so, not a lot but, you know, how you like [mimes spitting] and I went to t'doctors. But, like, er, I saw, it was a doctor who were, like , what do they call it? I'd never seen her before, like. What do they call it *a locum* a locum and, er, she were very nice and I said, 'Well, I've been, like, I've been, er , I've only come because I have a cough, but I've been spitting blood up, like.' 'Oh,' she says, 'Well, in that case, we'll see if we can get you into t'hospital.'

Reggie (87) despite having advanced lung cancer (and still smoking) was an active man, pursuing hobbies and interests which he said kept his mind from dwelling on cancer. In particular, he was regularly occupied in being attentive to the needs of others, his children, grandchildren and neighbours. He didn't regard himself as being in need of help and said he would rather give help to his children (aged in their 50s and 60s) than receive help from them. He had arranged to donate his body to medical science and organised all his finances so that there would be a minimum of trouble to his children in the event of his death. I interviewed him in October 2008 and he died in April 2009.

Reggie's account of his first symptoms, reported in a matter of fact way, tends to disguise, and normalise, what might be thought of as unusual. Aged 82 (internal evidence later in the interview) and having recently completed treatment for throat cancer, he flew to the USA to help his niece move house:

Now after this [treatment for throat cancer] erm, after I'd had this, I was feeling a bit, er,...this all came out, erm, my niece moved from Chicago to Arizona and she asked me could I go over and give her a lift. So, we hired a van and we went on route 66, the full nearly 2000 miles in five and a half days. And whilst I'm unloading, you know, the, erm, the, erm, van with the...everything's packed up, I felt a bit funny in the back, you know, and this was the first time I detected...

Jean (79) told a life story of many hardships including domestic violence, the violent death of one of her daughters (which sounds like murder but is never explicitly described as such) and a catalogue of her own illnesses. These included a very rare, non-malignant tumour which made her, to her apparent delight, a focus of special interest to the medical profession, and lung cancer.

Jean's mode of storytelling, proceeding by thought-association rather than by chronological sequence, makes it difficult to detect a particular starting point for her lung cancer. Even when she proclaims, 4500 words into the interview transcript, 'So, that brings me up to the big cancer I had in me lung,' she does not go on to tell anything of the symptoms but moves straight to an apparently random series of recollections and anecdotes about the radiotherapist, her GP and a long story about a dramatic allergic reaction to morphine, or, what she

called, 'morphine poisoning.' She never comes back to the starting point and I find during the course of the interview that, often, even when I ask what I think is a direct question, she gives me an answer that is oblique or which even seems like an answer to a different question. So, I never really find out how Jean's lung cancer began.

For most of the participants with colorectal or gastrointestinal cancer non-specific symptoms gradually became more troublesome and led to consultations with a GP. James (75, gastrointestinal cancer) experienced intermittent stomach pain and swelling, which he first attributed to overeating. His symptoms worsened on a holiday in the USA but he resisted his partner's attempts to have him check into hospital, determined instead to return home.

...and, er, then 19...no, 2000 we're into now aren't we, 2003, in September of 2003 er we went off to America, just for a two week's holiday.

and, er, but about a month prior to that I, er, I was feeling slight pain in my stomach and a little swelling but I thought I was overeating and it wasn't causing me any distress at all

but, er, got to America and, er, had a nice trip. But, erm, the stomach was still swelling slightly, but nothing that bothered me. So, came home off the holiday, was fine and then, erm, sorry, I've got that wrong, it was 2002, the first holiday there, but we'd enjoyed it that much in America that we decided we'd go again the following year, er, which we did. And, er, we went to New York and had five days in New York, thoroughly enjoyed... and during this time there was no pain.

And, er, then we flew down from New York to Orlando and whilst on the plane I felt pain and, er, our hotel was within three hundred yards of a hospital. Joan wanted me to go into hospital because my stomach was beginning to swell then. Anyway I decided not to. I didn't want to be hospitalised in America, erm, prefer to get home, which I did. And I went, er, we enjoyed the holiday of course, then came home and my stomach started to swell and that was in October of 2005.

Like Jean, Marjorie (74, colorectal cancer) tells a meandering story unconstrained by chronological or thematic sequencing. Invited to tell something of her life before she got cancer, she links in her opening sentence a short reference to a lifetime of good health, 'Well, I never went to the doctor's a lot,' with her reaction to the diagnosis of cancer: 'So, it were a shock really.'

The next two paragraphs of the transcribed interview contain more reference to her lack of serious illness, comparing herself with her eldest sister, born with a 'bad leg' but still living, and another sister who died eighteen months previously from bowel cancer and who had 'also been ill for years with blood troubles.' Marjorie reports a humorous exchange between herself and a clinician performing the endoscopy which preceded the diagnosis and concludes, in reference to the news that her cancer is operable, 'Well, you've just got to accept what they tell you.'

But to hear about the first symptoms I have to wait until sub-session 2 (see Chapter 4 p.100) of the interview and the opportunity to ask a direct question about what symptoms she was having which led to the endoscopy:

Oh, I were 'avin a lorra pains in me stomach, and I'd stuck it...well, I'd mentioned it to one doctor. He said me cholesterol were up and me blood pressure, t'nurse said, goes up. He said, 'It's up a bit, but it's good, good cholesterol,' he said, and took blood pressure. He said, 'Could be you coming here, could get you...'cos I only went once a year. So, they put me on a twenty four hour one. That were fine.

So, I did say to him, 'I've started, like, an ache, a stitch, in me side.' He said, 'Are you worried about anything?' Well, he [husband] were wi' me and he said, 'Yes, she is,' he said. Me sister's just being diagnosed with bowel cancer. He said, 'Do you think you've got it?' I said, 'No, oh no,' I said. 'She's got other things wrong with her,' so, just left it at that. I thought I must have strained it lifting, erm, that were 12 month after and she's been dead two years now, er, and it kept going worse and I thought, 'Oh, I'm gonna go and see him....'

The sequence of events is unclear, here, but it appears that Marjorie tolerated her symptoms of stomach pain for some time (she'd 'stuck it'), attributing the cause to a non-pathological source ('I must have strained it lifting'). During this time, though, she did have consultations with doctors about the symptoms and even mentioned a family history of bowel cancer, though discounting its relevance to her. The transition from this state of continuous symptom monitoring ('it kept going worse') to more focused help-seeking ('I'm gonna go and see him') reflects phases of what Ristvedt & Trinkhaus (2005) call 'Symptom Appraisal', the time taken to consider the seriousness of the symptom, and 'Action Appraisal', the time taken from recognizing the potential seriousness (or inconvenience) of symptoms to doing something about it.

Jack's wife told me, in his presence, when we first met at the oncology clinic that he is 'not gifted with words.' She was keen to talk to me as well, to give the carer's perspective, and we agreed that after I had interviewed Jack, I would give her an opportunity to talk on the record, again, in his presence, about her experience. Consequently, I was not surprised that my interview with Jack (79, colorectal cancer) produced the shortest sub-session 1 (see Chapter 4 p.100) of any of the interviews, at 3 minutes 5 seconds. In 262 words Jack gives a truncated account of his life story and the 'story' of his cancer.

I was born in 1929 and I liv...went through the war years. Started work at fourteen. I had one or two jobs, finished up in the...I went in the army. Come out of...went a job as a postman and after that I finished up at Leyland Motors for thirty years. After that I got married, I have two children, two lads pause and we come to live here in 1960, 1966 sorry. I've been here ever since. But, coming to the cancer thing, I never knew I'd got it because I'd no symptoms, anything like that. It was just a blow when they found out what it was. But can't do anything about it I don't suppose. So, just get on wi' it I think, that's all. Not much more I can say about that, really. But, t'only thing, I didn't want one of these bags. I don't like 'em. But what can you do? So, there you are. But otherwise you just get on wi life, that's all you can do really isn't it? You can't do nothing about it, unless you get a miracle or summat like that. So, I don't know but like [...] I've had very good treatment at th'ospital for it and can't grumble about that. So, just grin and bear it I suppose? Yeh

[pause] I know it's a blow to anybody that's got cancer but these things happen I suppose don't they? [pause] Well, that's about all I can say about I think, really.

One striking quality of this account is that it begins as a narrative which features temporal sequencing, geographical location, personal and social context (Clandinin and Connelly, 2000) but becomes, with the 'cancer thing,' an evaluative commentary which only hints at a narrative structure. For a hearer or a reader there is a tantalizing narrative gap between the phrases, 'I never knew I'd got it because I'd no symptoms,' and 'It was a blow when they found out what it was.'

Later in the interview, I try to fill this gap. Florence referred in pre-interview conversation, with the recorder not yet switched on, to Jack's visit to the GP with a chest infection. I try to find out how this turned into an investigation for bowel cancer, but I don't succeed in discovering what it was that made the GP refer him to hospital.

-Just take me through what happened, then, from going to the GP and what happened after that.

Well, I went...I'd to go to [named] hospital for a...the camera, I don't know what it's called. And after that, what they found, they said, 'We can't do it here. You'll have to go to [a different, named] hospital to have the operation done.' So, within about, I think, about a month, I were in [name] hospital having an operation [pause]. But, er, I wa'n't all that great when I'd had the operation. I were that weak, I don't know what were happening *afterwards*? Yeh, I hadn't strength to pick a paper up but, er, of course it takes time to recuperate.

In this exchange I think I am asking a 'narrative pointed question' (Wengraf 2008). I think I am asking Jack to tell me about what happened during his visit to the GP and then what happened after that. But, really, I conflate these two things and what John probably hears is, 'Tell me about what happened after you went to the GP' and goes on to tell me just that: 'I'd to go to hospital for the camera' ie endoscopy. I then go on to ask about the operation and I don't make the opportunity to return to that narrative gap, which remains unfilled (Florence

begins her account with the diagnosis). So, this remains one of two interviews, with Jack and with Jean, where the start of the cancer story remains unclear.

Florence does, however, indicate a retrospective reappraisal of Jack's symptom experience (loss of appetite and declining energy) which, with hindsight, is seen to have indicated that something was wrong:

One of the doctors at the surgeon's clinic said, after this operation, 'When you've recovered, you will feel better than you've felt for a long time.' And he (Jack) said, 'Well, I've not really felt ill.' But, when you look back, there were things not quite right. His appetite wasn't good. We kept saying, 'Well, when you're older you don't need as much food.' But his appetite had really gone right down. It was very difficult. Various little bits. And now that he feels so much better he realizes, now, yeh, there were one or two little symptoms and [...] But you don't put it down to a bowel tumour do you, you know. It's the last thing you think of; appetite gone- something wrong with his stomach, an ulcer or...but you don't...you would never put your mind to a bowel tumour.

Such normalising of symptoms experienced at an early stage of disease has also been noted in research with sufferers from lung cancer (Corner et al 2006, 2005) and breast cancer (Leydon et al. 2003, Nosarti et al, 2002).

Finally, in this section, Richard (79, colorectal cancer) gives a concise but brief narrative account of his early symptoms which, like several of the participants, continues seamlessly into a story of referral, investigation and diagnosis. The part referring to first symptoms is highlighted in bold script:

And the start of the cancer was, in a way, I suppose it was a good thing it manifested itself, er, by I wasn't able to go to the toilet. In fact, I hadn't gone for ten to twelve days, before I'd eventually got into hospital. The GP had referred me after seven days and I was there in ward 12, the assessment ward, and I'd had an x-ray there which they didn't seem to pick up anything specific and I was sent home with some medication.

That was over the weekend and, er, things were no better on the Monday, Tuesday and I went back to the GP who got me, er, sent back to the hospital immediately, then. And then I got... the treatment I'd had up to then tended to be by younger doctors and I hadn't...the consultant, N....I forget his name, great bloke there, he examined the x-ray and he could probably see a little bit more than they could and decided there was a tumour in the bowel.

5.5 Cancer detected by sudden and dramatic onset of symptoms

Henry (76, colorectal cancer), alone among the participants in *Cancer Stories*, experienced a sudden and dramatic start to the discovery of his bowel cancer, though he had experienced earlier symptoms of rectal bleeding which he attributed to haemorrhoids or 'piles'. Misattribution of symptoms, along with the normalising we have already seen, has been noted in various studies of patient delay in presentation (Corner et al 2006; Leydon, 2003). Henry tells what Wengraf (2008) calls a 'rich in-PIN' (Particular Incident Narrative): a story full of detail, told as though the participant is reliving the experience:

And, anyway, it came to a head last Christmas, in December. I had a brandy at me friend's house; there were seven of us going to this club and, er, we went in this club and, er, I got a pint of bitter. I can remember just having a few drinks and I thought, "Oh, I don't feel right [sounds indistinguishable] me stomach,' which were unusual for me because everything used to work normal. I'd go to t'toilet probably twice a day but no less than once a day. But I had been seeing blood and I thought it were piles so I'd been putting suppositories, you know.

And then, er, then I went to the toilet at the club. The blood as gushed out of me, I couldn't tell you what it were like. It took me ten minutes clearing everything up and washing everything down wi' a brush in this toilet. And I went back and I said to me neighbour, "I'm goin 'ome, I don't feel so good, but don't say owt to the others, I'm goin 'ome."

Well, I'd to walk about quarter of a mile from the club, you know. How I got home I'll never know , you know. I don't know.

I got inside and straight on the toilet and it was just gushing out of me wi' blood. So she rang for the ambulance and as soon as he saw me he said, "It'll have to be [name] Hospital for you. I'm not taking you to [name] or [name], it'll have to be [cancer centre]," you know. So, it were that bad I put a big towel between me legs and new pants on, new shirt and everything, to go out.

5.6 Summary

The NHS policy context which forms the background to the experiences reported by this cohort of older people is one of great concern about the late presentation of cancer coupled with a continuing drive to educate the public about cancer prevention (DOH, 2007). The cultural context remains one in which cancer is feared (Stacey, 1997) but where fear may contribute either to help-seeking behaviour-John's fear that he may contract prostate cancer and die from it, like his father and his brother-or to denial and the ignoring of symptoms (Pamela and Doris).

Findings reported in sections 5.2-5.5 show that, like up to 90% of people with cancer most of the participants in *Cancer Stories* began their experience of cancer with the symptoms or signs of disease (Richards, 2009). Only one cancer was detected by pre-symptomatic screening. There were lengthy delays to investigation and diagnosis beyond the first signs in some cases, as reported in other studies (Allgar & Neal, 2005; Leydon et al 2003; Richards et al 2009). This occurred most noticeably where participants ignored the signs and symptoms of disease (Doris, Pamela) and where initial investigations failed to detect malignancy (John).

Ramirez et al (1999), in a systematic review conducted to assess the quality and strength of evidence concerning risk factors for delays to diagnosis (both

patients and providers), found strong evidence that older age is a risk factor for patient delay. Arndt et al (2002), in a population-based study of 287 women with newly diagnosed breast cancer, found that patient delay of longer than three months was reported three times more often in women older than 65 years. Nosarti et al (2000), found, by contrast, that delay was associated with psychiatric morbidity but not with age.

Ristvedt & Trinkhaus (2005) draw attention to this inconsistency in the literature of the association between patient delay and age. An important reason for patient delay in their study of 69 patients with rectal cancer was the tendency to minimise, or 'normalise' their symptoms. Corner et al (2005, 2006) also found this in people with symptoms of lung disease and Nosarti et al (2000) in women with breast disease. Of the *Cancer Stories* participants with rectal, or gastrointestinal cancers, this was true of Margaret, James and, to some extent, Jack. Richard and Henry both presented promptly with unmistakable symptoms of pathology. Richard visited the GP after enduring a week of constipation and Henry experienced sudden and copious rectal bleeding (though, as we have seen, he had misattributed earlier episodes of bleeding to haemorrhoids). Two of the participants with lung cancer reported early symptoms but misattributed them to other causes: Daniel attributed his weight loss to statins and Alec initially believed his chest symptoms to be caused by infection.

Physician delay (sometimes called 'provider' or 'system' delay in the literature) seemed rarely to feature in the experience of these older people. For most participants who reported troublesome symptoms to their GP investigations were ordered promptly and diagnosis made in a timely manner (but there were notable exceptions to the timeliness and accuracy of initial diagnoses; see Chapter 7). Alec's doctor insisted on referring him to the chest clinic on his second appearance at the surgery with symptoms; Daniel's GP responded to his symptoms of breathlessness by referring him instantly to the hospital, with 'no further ado.' Michael's doctor listened to his symptoms, asked him some questions and said, 'I'll make you an appointment.' When Bill reports spitting blood the locum GP's response is, in Bill's words: 'Oh, in that case we'll see if we can get you into hospital.' There was a delay in diagnosis for Marjorie, probably because of her non-specific symptoms ('an ache, a stitch in me side')

and for Richard because he was at first attended to by junior medical staff who misinterpreted his x-ray. James delayed presentation because of his non-specific symptoms, but delay was then compounded by initial misdiagnosis (see Chapter 7).

In the next chapter I report in more detail the ‘cancer stories’ which tell of participants’ experiences of, and reactions to, the diagnosis of cancer.

Table 5.1 First Symptoms and Medical Consultation

Name	Screening	Signs	Symptoms	1st medical consultation
Breast Cancer				
Anne		Breast lump		Immediate self referral GP
Barbara		Nipple change		Direct to hospital
Doris		Nipple change		Delayed self-referral GP
Maria		Nipple change		Immediate self-referral GP
Pamela			Axillary pain	Delayed self-referral GP
Colorectal Cancer				
Henry			Rectal bleeding	Emergency hospital admission
Jack			Apparent chest infection	Self referral GP
James			Stomach pain and swelling	Self referral GP
Margaret			Stomach pain	Self referral GP
Richard			Severe constipation	Self-referral GP
Lung Cancer				
Alec			Apparent chest infection	Self-referral GP
Bill			Coughing blood (haemoptysis)	Self-referral GP

LIVING WITH CANCER IN OLD AGE:
A QUALITATIVE SYSTEMATIC REVIEW AND A NARRATIVE INQUIRY

Daniel			Loss of appetite and breathlessness	Self-referral GP
Jean			Unrecorded	Unrecorded
Reggie			Lower back pain	Self referral GP
Prostate Cancer				
Bernard			Frequency, hesitancy	Self referral consultant (privately)
Clive			Frequency, hesitancy	Self referral GP
Don			Dry throat 'waterworks not too brilliant'	Went into hospital (bypassed story of self-referral to GP)
John	Private			Self referral GP
Michael			Frequency, nocturia, dribble	Self referral GP (encouraged by friend)

CHAPTER 6

'CANCER STORIES': ANALYSIS AND INTERPRETATION OF FINDINGS (2)

DIAGNOSIS AND REACTION

6.1 Introduction

For anyone facing cancer, either because they have suspicious symptoms or because they have received a positive screening result, it is important that diagnosis is timely and accurate and that the information is conveyed sympathetically. In this chapter I present and discuss findings relating to the accuracy of diagnosis, the disclosure of diagnostic information and participants' reactions to the diagnosis. As we have already seen (Chapter 5) for several participants, investigations and diagnosis followed swiftly on presentation of symptoms, the diagnosis was accurate and treatment initiated quickly. For some, though, there were delays in the timeliness of diagnosis, affected by various forms of slowness to seek medical help (ignoring of signs and symptoms; 'normalising' or misattribution of symptoms). For some there was physician delay caused by initial inaccuracies in the diagnosis. Where participants report the manner of disclosure there is apparent deviation from concordance with standard practice. Reactions to the diagnosis range from shock to stoical acceptance.

6.2 Accuracy of diagnosis

For some participants, the timeliness of diagnosis was affected by initial inaccuracies in the results of their medical investigations. There was a lengthy delay in the diagnosis of John's prostate cancer as, in his report, the 'top man' whom he went to see ('well up in the prostate cancer field') had to perform more than one biopsy, with a gap of two years, before the diagnosis was confirmed:

He went through it and in the end said, 'I think perhaps we'll do a biopsy' but, er, not to worry; and they did and they found nothing. But I was in

his hands then and went back regularly and he did another biopsy a couple of years later when he did find it. And I think, in fairness [John uses this phrase repeatedly during the interview] he said that the original one had missed it. So, there was something there. And, er, that was at the time I was just coming up to retirement, just coming to 65. And he sa...his view was that we wouldn't operate, but we could treat it with drugs.

James's gastro-intestinal stromal tumour was initially diagnosed as cancer of the pancreas, and presented to him as a disease with a fatal outcome:

But it was better, er, than what a doctor said to me on the 24th of December, sat in this very room. I sat in this seat here. She sat on the settee over there, and told me she was sorry but I'd cancer of the pancreas and it wasn't possible to live. Er, to say I was shocked, erm, [with rising inflection]. I've since seen her, about four months ago, and she was in shock, then, because she never expected to see me again.

Other participants, too, were given provisional diagnoses, in these cases reassurance of non-cancer, which turned out on further investigation, or re-interpretation of original tests, to be mistaken. Over a series of investigations Henry's diagnosis moved from, 'It's an ulcer has burst,' to 'I've bad news for you, Mr. Jameson, you've got bowel cancer.' Maria experienced a sequence of false reassurances: from a GP who examined her inverted nipple and concluded, 'It's not worth bothering about really, it's not gone right in'; to a mammogram report which 'came back I was clear'; to the assurance that the removal of a small lump would be sufficient and, 'You won't need to have radium or your lymph glands removed or anything like that.'

And I'm getting undressed to go to bed [...] and I thought, 'Gosh, me nipple's going in. What's wrong with it? [...] So, I went to the doctor's, I have a lady doctor, and she says, 'Let me look love.' So, she's fiddling about. She said, 'Do you know,' she said, 'It's not worth bothering about, really,' she said. 'It's not gone right in,' she said. 'But never mind, I'll send you for a mammogram, be on the safe side.'

So, I go for this mammogram. Now, it's two years next month, March, and it came back I was clear, nothing wrong with me. And I thought, 'Thank God, ohh!' And a couple of weeks after I gets a phone call. 'Er, this is the nurse from wherever,' she said [...] 'are you by yourself.' I said, 'Yeh.' She said, 'Well, can you get somebody with you cos we're coming to see you,' she said. Ohhh! Then, I'm sat where you are, and they tell like they're saying you've got the flu, you know.

So, she sits there and she said, cos me cousin came, and she said, 'Er, right love,' she said, 'er, you've got breast cancer.' [pause] And I looked at her and she said, 'Yes,' she said, 'You see, we've found a shadow and we'd like you to come for a biopsy.' [...]

So, I went for this biopsy and I went for some kind of a scan where you stand at front of a thing. I had that done, then I got a letter to say, 'Yeh,' and as I'd to go in. Now, I saw a lovely specialist before I went in, ooh he was nice, and he said, 'Now, you've got a very, very small lump. It's not really worth talking about,' -cos me sister kept saying, 'I don't think you should have gone at all.' -'Very small lump,' he says. 'But we'll remove it,' he said, 'and you won't need to have radium or your lymph glands removed, anything like that.' 'Oh, right,' I said. Ohhh! [my marginal note in the transcript at this point reads: 'sighs with raised eyes as if to say, 'Oh yeh? Believe that!']¹⁶

In the event Maria had lymph nodes removed as well as the breast lump, followed by radiotherapy. At the time of the interview she was continuing to receive treatment for lymphoedema in her hand and arm. She expressed no real criticism of any of these health professionals though her facial expressions, non-verbal exclamations and some of the phrases she used ('so, she's fiddling about'; 'they tell you like they're saying you've got flu') indicate that she doesn't think very highly of their professional behaviour or their manner of communicating.

¹⁶ Cf Gubrium & Holstein, 2009, p75: '...physical gestures such as upturned or downturned hands and rolled eyes can add recognisable meaning over and above what is actually said.'

6.3 Disclosure of diagnosis

There is wide cultural variation in the practice of disclosing a diagnosis of cancer. In the UK and North America the key concern tends to be the manner in which the diagnosis is disclosed (Mager & Andrykowski, 2002; Salander, 2002; Thorne et al. 2009). There is rarely any question that the patient should not be told the diagnosis, though as recently as 1998 the authors of a cancer management textbook published in Britain could write, ‘Nowadays patients should **seldom** (emphasis added) be in total ignorance of what is wrong with them or what the treatment involves,’ (Souhami & Tobias, 1998 p 4). In cultures where the family is more dominant than the individual, or where there is strong religious belief, disclosure of a cancer diagnosis is often embargoed by relatives (Ozdogan et al 2009) despite evidence that patients themselves want information (Kendall, 2006; Tse et al 2003).

Diagnosis of cancer is a significant part of the illness trajectory. It may be anticipated by the patient after a series of investigations which follow the first symptoms or signs. It may be feared, consciously or sub-consciously, in the delay which sometimes precedes help-seeking following the experience of first signs (Doris and Pamela in Chapter 6). The diagnosis of cancer may come as a complete surprise (see Bill’s story in this chapter). Cancers are complex disease processes and are not always easily detected. The presence of malignant disease may be missed or inaccurately perceived (see John, Richard, Henry, Maria and James’ stories in this chapter).

In contemporary clinical practice in the United Kingdom an ‘open awareness context’¹⁷ (Glaser & Strauss, 1965; Seale et al. 1997), whereby the diagnosis of cancer is disclosed and treatment options are discussed between clinicians, patient and family members, is now standard practice (Innes & Payne, 2009). It was not so in a previous generation¹⁸ and some evidence suggests it is still not

¹⁷The setting in which Glaser and Strauss devised this schema was in relation to patients’ awareness of dying in hospital. I think the principles may be usefully applied to earlier stages of the illness trajectory.

¹⁸ Letter from the Duchess of Devonshire to her lifelong friend Patrick Leigh Fermor, 11 Sept 2004, on re-reading old letters: ‘Nancy’s four years of torture (1969-73) all came back with a bang. Dear me. Would it all have been better now, doctors more merciful etc? She would have

universal.¹⁹ As treatment for cancers has improved, bringing greater expectations of cure, the threat of cancer as an inevitably terminal illness has receded, though among the general population the fear of cancer remains high. Since the diagnosis of cancer may not now be always seen as a ‘death sentence’ this may have influenced attitudes and behaviour in the direction of open disclosure. In the setting for *Cancer Stories* all participants had been informed of their diagnosis. It was less easy to determine the extent of prognostic information which had been disclosed or, indeed, desired (Elkin et al 2007; Innes & Payne, 2009).

The manner in which study participants had been told the diagnosis, where it was reported, did not always conform with best practice. The reactions of participants to poorly conducted episodes of ‘breaking bad news,’²⁰ as the disclosure of a cancer diagnosis is known among health care professionals, contrasts with findings from the literature which suggest that where ‘bad news’ is broken poorly (ie bluntly, insensitively, without warning or adequate follow up) there may be long term psychological consequences for the patient along with damage to the clinician-patient relationship (Mager & Andrykowski, 2002). Participants in *Cancer Stories* did not seem to be unduly perturbed by the experience of poor disclosure practices. They were not even particularly critical of practitioners whose practice may be deemed, according to some of the stories they told²¹, less than satisfactory.

Bill told a story of diagnosis disclosure which suggests sub-optimal practice:

It were a shock when he told me, t’doctor. He were very... not sayin’ he were blunt, that’s his job, innit? And I were glad it were...he told me that, like, right away. But it’s still a....when you get to know. By gum, I nearly collapsed, like, *um*, when he told me *um*. Because, like I say, I wasn’t

been told she’d got cancer, no more whispering in the passage with the doctors, at least I do believe it’s better to know.’ (Mosley, 2008, p.345).

¹⁹ ‘No reference was made to the patient’s diagnosis, as some patients are not aware of their condition’ (DOH, 2005 p43). National Audit Office description of survey methodology for their study ‘Tackling Cancer: Improving the Patient’s Journey’.

²⁰ In Cancer Patient Surveys in 2000 & 2004 in England (DOH 2005 p2) 94% of patients reported being told the diagnosis with ‘sufficient sensitivity and care.’ In Thorne et al’s Canadian study of 60 patients 42% reported ‘decidedly negative communication experiences during the diagnostic period.’ (2009, p. 1385).

²¹ I follow Thorne et al (2009) in being careful not to impute poor practice to clinicians based on the patients’ reports. They use the word ‘difficult’ to describe patients’ perceptions of some communication with health care professionals.

expecting it. And he just, like, come out wi' it and said, 'You've got a tumour.' And I thought, 'Whew, dearie me. ' I were a bit upset. I didn't show anything there, at th'ospital [sic], but I were a bit upset when I come home, like, really, you know. But, er, that's what it is. They said they couldn't do anything, or, it just has to be. [I interviewed Bill in June 2008. He died in November 2008]

As reported by Bill, this doctor's manner of communicating a diagnosis suggests unfamiliarity with standard methods for 'breaking bad news' (Buckman, 1992, 1988; Kaye, 1996) in which, among other things, the extent of the patient's knowledge is gauged, signals are given that bad news is coming, sympathetic expressions are used and the patient is left with some grounds for hope²² (Bain & Campbell, 2000; Eliot & Olver, 2002; Thorne et al. 2009).

Despite the strength of Bill's reaction ('It were a shock...I nearly collapsed...I were upset when I came home') he softens any criticism of the way he is given the news ('Not sayin' he were blunt,' despite 'I wasn't expecting it. And he just, like, come out wi' it and said, 'You've got a tumour') showing a forgiving and understanding attitude (it's the doctor's job to tell me and I'm glad he told me straightaway) to this apparent breach of good practice. This tolerance is in marked contrast to what might be expected from the literature on diagnosis disclosure (Mager & Andrykowski, 2002; Thorne et al. 2009)

In Don's story the disclosure of diagnosis is given as bluntly as his description of the digital examination which precedes the scan, an investigation which presumably confirms the diagnosis and enables the doctor to proclaim: 'You've got cancer.' Like Bill, Don offered no direct criticism of this approach, but neither did he excuse it and his language and his laugh give some hint of a critical attitude.

I went in to hospital and this Indian guy [...], poked his finger up [vigorous gesture] and things like that and said, 'Oh, umm, you'll have to have a

²² This is not straightforward. Elliott & Olver argue (p.188) persuasively that hope is both 'vulnerable' and 'enduring'. Its vulnerability implies a responsibility on the part of health professionals to preserve it. But its enduring quality makes it impervious to any attempts to alter or remove it, rendering any such attempt futile.

LIVING WITH CANCER IN OLD AGE:
A QUALITATIVE SYSTEMATIC REVIEW AND A NARRATIVE INQUIRY

scan.’ ‘You’ve got cancer,’ you know. There was no...just bang, ‘You’ve got cancer’ [chuckle], you know.

Daniel ‘had an idea that something was amiss’ and he was informed of the diagnosis on a ward round, in a paternalistic style which perhaps used to be typical and which still persists²³:

I just had that feeling, as one does I suppose, the doctor, [...] and his colleagues, students, quite a group of them grouped around everyday, he came up there to the ward and grouped round and discussed various things, not in my earshot but I could tell he was discussing something of importance to somebody. And, eventually, he arrived at my bed with the whole gang of them and duly informed me that they had found cancer of this particular type, what’s it called now? Mesothel-omia (sic) something like that, which was an unusual type in the sense that people haven’t recognized that they’ve got it. And I presume you don’t recognize you’ve got it because, erm, apart from the fact that I had lost appetite and such like I hadn’t a clue. I had no pain with it.

Daniel did not comment directly on the manner of disclosure but his descriptive language (‘not in my earshot’; ‘something of importance to somebody’; ‘eventually arrived at my bed’; ‘whole gang of them’; ‘duly informed me’) indicates a rather impersonal and over-formalised approach on the part of the doctors which may be thought less than fully respectful of the individual.

Participants in this study seemed to be tolerant and forgiving when they received a less than complete service (false reassurance, delayed or inaccurate diagnoses, unsympathetic disclosure) and one begins to get the impression of a cohort effect whereby older people, unused to the role of modern consumer with high expectations of choice and quality in all services, do not complain or voice, or even feel, dissatisfaction.²⁴

²³ See extract from Macmillan Cancer Relief ‘Open Space’ report (2000) quoted in the NHS Cancer Plan (DOH 2000, p64: “*If only the surgeon would talk to me properly-they arrive in a group of five round my bed....and he talked quickly to me-he discussed something with them and moved on. I had no chance to ask questions..*”

²⁴ Satisfaction with pre-diagnosis GP care, for example, increased with age in the NAO Cancer Patient Survey (DOH 2005, p 9), rated as very good by 71% of people aged 81 years or over compared with 50% in those aged 16-35.

Some participants expressed, on the contrary, a great deal of satisfaction. Doris expected to be ‘told off’ for not seeking help sooner. She finds, rather than the reprimand she expects, a positive affirmation of a caring attitude, particularly from an oncologist:

He was extremely kind, you know and he sat and talked to me [...] He was very good, you know, he put it to me he wasn't nasty or anything like that he put it to me [ie. Told me I had cancer) and I said, ‘I'm sorry I've waited so long,’ and he never said anything, you know. And when I went to see the oncologist after you know, I said, ‘I've been very naughty. I should have come sooner.’ She said, ‘We're not here to, you know, reprimand people; we're here to look after you,’ you know. So, I thought, well, that was very good, you know. That puts your mind at rest a bit, you know. Cos you're a bit afraid of being told off you know. Well, I never got anything like that. As I say, I've been very well treated. And I have nothing [bad] to say about the National Health Service whatsoever, they've been very, very good to me.

In some participants' cancer stories the disclosure of the diagnosis is absent (Jean, Michael) or referred to fleetingly (Clive). The story of Clive's diagnosis, for example, was buried in his wife's report that, ‘The doctor referred him to go to hospital to see [specialist] because he was spendin' a penny, stoppin', and then he'd go again...that was the start of it.’ Clive himself began his story post-radiotherapy and I never found out how his cancer was diagnosed.

6.4 Reactions to diagnosis

Where they are reported, participants' initial reactions to the news that they had cancer range from the shocked (Anne, Bill, James) to the stoical (Reggie, Daniel, Doris). The overall and longer term reaction, for most, is one of fatalism. Anne was emotional as she recalled her feelings when she was told she had cancer and, alone among these participants, linked her reaction to her religious faith:

But the day the doctor told me I had cancer, God I near died [holding back tears] *um um I bet, it's a shock to hear isn't it?* It is indeed. But I've put my trust in God [tears breaking into and through voice]. I don't know

whether you believe in God or not but he just said he would look after me and so he did for so far.

We have already seen, in his story of the diagnosis disclosure (p.147), the strength of Bill's shocked reaction, such that he 'nearly collapsed' at the news. James, too, told of his strong feelings in reaction to his eventual diagnosis of a gastric tumour:

It's, er, very, very disturbing when you get the news, er, that it's malignant when they've done a biopsy and then relating it... the partners, Jean and the family and you see the, the grandchildren J at 10, well he's ten now, this year and L who's five this year of course that brings a lump to your throat when you've met them. But, of course, you don't tell them that you've got this. Their parents, my son, A. tries to explain that grandad's not too well.

On the other hand, Reggie 'took it on the chin' when told, sympathetically, of his lung cancer:

They gave me an x-ray and a scan and everything. 'Well,' he says, 'I'm sorry to tell you this,' he said, 'but you know you have lumps in both... you have cancer in both your lungs.' 'Oh,' I said, 'that's not good is it?' 'Cos I can take things, quite truthfully. I wouldn't drop through the floor because of that. So I took it on the chin. And he says, 'I'll arrange for you to come and have radiotherapy.'

Daniel, too, reveals a stoical attitude, which is of a piece with the fatalistic world view he shows at several points in the interview. And he maintains this outlook in spite of his family history of cancer, differentiating his own experience from his father's:

After they told me, it didn't worry me. Alright, cancer's a big word to some people, they're frightened to death of it. Now, my father died of bowel cancer, a few years ago now, and he had quite a lot of pain, you see. But I was fortunate, as I say, no pain.

Fatalism seems to run deep in this cohort of older people. Facing his own diagnosis of lung cancer, and the recent death of his wife, Alec tries to 'be

positive and get on with things.’ Jack describes the news as ‘a blow’ but in the space of 182 words utters six sentences which are variants on the theme of ‘grinning and bearing it.’

But can’t do anything about it I don’t suppose.

So, just get on wi’ it I think, that’s all

You just get on wi life, that’s all you can do really isn’t it?

You can’t do nothing about it unless you get a miracle or summat like that

So, just grin and bear it I suppose?

These things happen I suppose, don’t they?

Jack’s wife, Florence, encapsulated the tensions involved in receiving news of the diagnosis as a shock (Jack had no obvious symptoms and they had no family experience of cancer) and in then trying to balance the attempt to be positive with the all-too-real feelings of despair and hopelessness:

Well, it was a shock when he...when they said...first of all they said he’s got a “tumor” and still you think, ‘Well, yeh, fine but it’ll be alright.’ But then when they say, yes, it is malignant, it suddenly dawns on you that things are... your life’s gonna change, I suppose, which it did. They were very prompt with his treatment and everything, but I don’t think you envisage the impact it’s going to have. They sent him home from hospital extremely weak which I don’t complain about because I don’t think he would have got much stronger on the ward. He improved quickly. But the difficulty for me, and probably for most partners, is trying to keep the morale of the patient up when your morale is down there and trying to talk positive and feel positive and say, ‘You’re alright, we’re alright, we can do this,’ about it and all the time you’re in despair yourself.

Doris is not shocked by news of the diagnosis because she ‘knew what it was, you know, you couldn’t...I knew exactly what it was.’ Her reaction, too, is one of fatalism. She repeatedly talks of just having to ‘get on with life.’

You know, it wasn’t a shock when they told me, you know, and I thought, when they did, eventually, tell me, I thought, ‘Well, that’s it, there’s nowt you can do about it. Get on wi’ it, face it full on and do it. And that’s what I’ve done, you know. So...and up to now, touch wood, you know I’m alr...I feel alright. I don’t feel it’s a burden or I don’t, I don’t let it bother me in

any way. I just get on, you know. I just get up in a morning and I think, 'What have I to do today?' and I get it done, you know. I do me garden, I do all sorts you know. I think 'Well, it's there, deal wi' it, like I do all that wi' problems, you know. I think, 'It's no good covering it up. But I did that with me cancer and I wish now I hadn't. I wish now I'd been a little bit stronger, you know, and gone earlier, cos I wouldn't have had all that worry, all that time, you know. So I, now, I say to people, you know when we're in conversation, I say, 'If you've any problems or anything GO! Straight away, don't delay, go!' you know. So, I hope I've, you know passed it on to somebody. But I'm alright and, I mean, I'm 76 I shall be 77 in a couple of months. I haven't done so bad have I?

6.5 Summary

The 'diagnostic pathway' (Corner et al 2005), represents a period of time which extends from the first awareness of symptoms through a decision to seek medical help and the undergoing of investigations, and concludes with the pronouncement of a diagnosis. This is a complex process. As we have seen, a number of variables affect the timeliness and accuracy of a diagnosis, including: the patient's recognition of a suspicious symptom and their decision whether or not to act on it; the speed of referral from general to specialist practitioner; the accuracy of initial investigations. In addition, the presence of comorbid disease in older populations may complicate the assessment of multiple pathologies. There was no direct evidence of this in the stories told by participants in *Cancer Stories* but it may be thought unlikely that individuals would have sufficiently detailed knowledge of the disease processes competing in their bodies to be able to talk about this at length.

Cancer remains a disease which, at least in the minds of the general public, represents a serious threat to health, or to life itself. Consequently, the appropriate disclosure of the diagnosis has been a matter of concern for clinicians and researchers alike. Recent studies reveal different foci in different countries and varied clinical settings. Some studies concentrate on measuring patients' awareness of diagnosis or prognosis (Cavanna et al 2007; Montazeri et al 2009; Numico et al 2009). Others investigate patients' preferences for

knowing the diagnosis (Cavanna et al 2009; Goncalves 2005), or physician attitudes to disclosure (Jiang et al 2006; Mobeireek et al 2008). Elkin et al (2007) specifically investigated older patients (70+) preferences for prognostic information and involvement in treatment decisions. Repetto et al (2009) claim that there is a lack of specific studies on patterns of clinical communication in elderly patients. For some researchers the topic of interest is patients' satisfaction with what is told and the manner in which it is told (Gabrijel et al 2008; Geiser et al 2006). And, some UK and North American studies (Randall & Wearn, 2005; Tobin & Begley, 2008) have turned their attention from the *disclosure* (physician/provider focus) to the *receipt* (patient focus) of the diagnosis and emphasized the nature of receiving and understanding bad news as a process occurring over a period of time, rather than as an isolated incident.

In *Cancer Stories*, participants were invited to talk openly about their experiences, without being specifically prompted to recall particular events. Some participants spoke about an occasion on which the diagnosis of cancer was disclosed though, for the most part, this represented one of several steps in a process of coming to know they had cancer (Tobin & Begley, 2008). And all the participants *did* know that they had cancer. In one study, by contrast, 72% of a small sample (n=47) of patients with advanced cancer thought they had been informed of their diagnosis but not all of them stated the diagnosis in a manner which showed clearly that they were aware of the nature of their disease (Goncalves et al 2005). And, despite claims that patients want and need to be adequately informed, Brokaliki et al (2005) found that nearly two-thirds of 203 patients surveyed claimed to have no knowledge of their diagnosis. The manner in which diagnosis was disclosed did not, in the reports of participants in *Cancer Stories*, always conform with recommended practice and it will be one of the recommendations arising from this research that continuing effort be made to educate and support clinicians in the conduct of this important task.

The extent to which prognostic information had been disclosed, or received, among participants in *Cancer Stories* was difficult to gauge. Four of the five participants with lung cancer indicated that they knew 'nothing could be done' and that any treatment they were receiving was for the relief of symptoms. Reggie was the only one to refer, in a pragmatic way, to his likely imminent

death. Don had been made aware that his prostate cancer was advancing and he spoke of this in terms which suggested he now knew his lifespan was likely to be curtailed. As we will see (Chapter 8, p. 186) he was determined not to let this knowledge slow down his plans for a new business venture. Jack and Florence had been made aware that Jack's rectal cancer had spread to his liver, but what this meant for the future remained a source of uncertainty for them.

The diagnosis of cancer poses threats to physical and emotional well-being and is a significant stage of an illness trajectory. It forms the basis for decisions which are made about treatment of the disease. Participants' experiences of treatment are reported in the next chapter.

CHAPTER 7

'CANCER STORIES': ANALYSIS AND INTERPRETATION OF FINDINGS (3)

TREATMENT

7.1 INTRODUCTION

Treatment is a significant milestone on the cancer trajectory. All the participants in this study received some form of treatment for their cancer; even if the disease was deemed to be incurable they received palliative treatment. Many of the participants received multiple treatments including surgery, chemotherapy, radiotherapy and other drug treatments. In this chapter I report the subjective experiences of treatment told by participants under three headings: i) overall satisfaction with treatment; ii) the process of decision-making; iii) the effects of treatment. I illustrate these themes with detailed extracts from the narrative interviews.

It should be noted at the outset that the word 'treatment' connotes two meanings, both of which are relevant here. The first definition of 'treatment' which appears in the Shorter Oxford English Dictionary is *the process or manner of behaving towards, or dealing with, a person or thing*. Many participants spoke about their overall 'treatment,' in this sense, at the hands of the healthcare practitioners and systems they encountered during the course of their illness. They also spoke, in more or less detail, about treatment in a second sense, defined in the Shorter OED as, *the application of medical care or attention to a patient, ailment etc or subjection to the action of a chemical, physical or biological agent*.

7.2 Overall satisfaction with treatment

Eight participants made evaluative comments, in the course of their narrative, about their treatment in the sense of the first definition quoted above: *the process or manner of behaving towards, or dealing with, a person or thing*. For

the most part, they expressed satisfaction, sometimes in terms of glowing praise, with the way they had been treated. Daniel ‘nothing but praise for the whole concept of the treatment I received, from start to finish.’ James echoes this eulogy, saying, ‘I just wish everybody that gets cancer has the reassurance that I’ve had and the treatment that I’ve had. I definitely can’t say enough about the treatment I’ve had, how good it’s been.’

Three participants told brief stories to illustrate how good their care had been. Speaking about a consultant oncologist, Reggie said:

She’s done a lot for me. Anything I ask for, like blood tests and that sort. I once asked her for a blood test. And do you know when I got the blood test? The doctor phoned me here, at night, could I go to hospital the same night? And they pumped four pints of blood into me. I was anaemic.

Clive showed his appreciation of the treatment he received by making small, periodic donations to the Cancer Centre:

I’ve got to say that they’ve looked after me really well, there’s no doubt about that. Sometimes I do, well, now and again I give ‘em a few quid for appreciation for what they’ve done for me. And they appreciate that, because they always acknowledge with a letter, saying that they thank me. It’s not a regular occurrence because, I mean, still, old age pension, you know [chuckles]. I do it when I can.

There is mutual regard, too, in Doris’s story of satisfaction, when a nurse tells her ‘It’s been a pleasure nursing you.’ This raises an intriguing question about the dynamic nature of the relationship between individuals, and between individuals and a system. It may be not, simply, that individuals receive a service which they perceive to be ‘good’ and which, therefore, gives them satisfaction. It may also be that some individuals bring personal qualities to a relationship with health care providers which affects the quality of the service they receive. This has implications for the so-called ‘unpopular patient’ (Johnson & Webb, 1995; Stockwell, 1984).

I can’t complain about me ‘ospital treatment or anything, no complaints at all [...] I went in on the Thursday and I came home on the Tuesday and

LIVING WITH CANCER IN OLD AGE:
A QUALITATIVE SYSTEMATIC REVIEW AND A NARRATIVE INQUIRY

one of the nurses, she were lovely, she put her arms round me and she said, ‘ta-ra Doris, it’s been a pleasure nursing you.’

Doris took the opportunity to record her feelings of satisfaction formally when she received a patient satisfaction questionnaire:

So, I filled it in, and, at the end it said, ‘Any comment?’ So, I thought, ‘Right.’ So I put it all in: ‘I was treated with the utmost respect’...and...two things...kindness and respect. And I was. So I wouldn’t be afraid [of having to go into hospital again]. And that’s what I tell people, now, ‘Don’t be frightened,’ you know, ‘you’ll be treated extremely well.’

In the reports of three participants, expressions of satisfaction, though made forcefully, were qualified. Henry’s experience of nursing staff was positive, and, at first, expressed unequivocally. But it was marred slightly by the apparent indifference of some nurses:

I was in hospital a month and day, and I couldn’t have been looked after better. But there were different ones that were a bit, ‘off,’ you know, like, didn’t have much time for you. But most of the time, I mean, the matron on there, M. she were absolutely marvellous wi’ me. And a lot of ‘em were, you know. Most of ‘em were. There was only odd ones as were, you know, like they couldn’t bothered if you shouted [for help] or rang your bell.

For Pamela, ‘They were lovely, the whole nursing staff, and everything, was lovely.’ But there were two sources of dissatisfaction. She felt ‘a bit let down’ because ‘nobody’s been in touch’ since her discharge from hospital, and it falls to her relatives to activate some support from the Social Services department, with which she *is* satisfied:

Me daughter-in-law was here and I was having a job showering [...] and I said to her I was going to buy a stool. I said ‘They’re selling them in Lidl’s.’ And she said, ‘No,’ she said, ‘You shouldn’t have to do that.’ But me daughter had been telling me to get in touch with the [cough] social....you know, and I kept saying, ‘No, they won’t do nowt for you, they won’t do nowt for me,’ you know. Phone goes, and it’s this person

and she says, 'Your daughter-in-law's been in touch with us. I believe you had an operation for cancer and you're struggling to hold yourself up in the shower to shower yourself, can we come to see you?' 'Yeh, certainly.' That's where I've got the stool from. And they put me a grip in the shower and a handrail down the stairs. And I find that brilliant for coming down the stairs, 'cos I've a struggle getting up and down, you know. I don't suppose I look too bad, but I do struggle.

A second source of dissatisfaction for Pamela arose from what she perceived as the abrupt manner of a doctor when Pamela queried a prescription:

[The] first time I saw her she was alright. But, the second time I saw her and she prescribed me Calcichew. 'The only thing,' I said, 'I did read the list of what could...now, I've three sisters, thrombosis,' I said, 'and it said on these it could be thrombosis.' Well, she wasn't very nice. I mean, you tell them these things don't you? 'Cos they asked me before the operation had I had anything? I said, 'The only thing is, I've three sisters with thrombosis.' Our M. was really bad, she nearly died with it. And they were very good in the hospital, 'cos they said, 'Well, now, we'll put it down here and we will keep an eye on things.' But she wasn't very nice when I told her [...] 'Well, er, can't really give you anything else. Let me see can I give you something else.' She was very abrupt with me, as much as to say, 'You should take these and just be...', you know.

Bill's expressions of satisfaction with his treatment, in the sense of his positive interactions with individuals, come as a qualification to his *dissatisfaction* with what he perceives as everybody's (fellow patients and staff) avoidance of talking about his illness:

It's funny, when you go for these [treatment] sessions, and you're meeting all kinds of people, aren't you, but nobody talks about it do they? You know, it's niceties, 'Oh, how are you? Are you alright? Nice to see you.' But, nobody ever mentions about being ill and what you have [incurable lung cancer]. They just steer away.

Bill speaks about this at length, repeating himself many times (exceeding even his characteristic manner of saying the same thing over and again) as though it is a matter of great significance to him. He describes just one incident when a fellow patient's husband spoke openly about her cancer and speculates on the reasons why people don't talk about serious illness, contradicting the male stereotype of strong silence in his preference for open discussion. (Interestingly, though, even he doesn't use the word 'cancer' to describe his illness. He tells his friends he has a 'tumour.')

There were only one woman that ever talked about it, what we met, only one woman. It weren't her, it were her husband, they were open. And I said, [to his wife], 'Isn't that surprising, she's the only person out of all them people we met who's mentioned about being ill.' It's funny isn't it, how people are? But, if people don't want to talk about it, well, fair enough isn't it, like, you can't alter that, can you? It 'appen upsets 'em. But, you'd think, like, if they did talk about it, it would 'appen help, like, wouldn't it? But, they don't seem to want to. I know it's a time when they can be worried, and things like that.

He elaborates on the hospital staff's avoidance of talking, while praising their skill in the delivery of his treatment. He tries to explain away their failure to talk about being ill, but his repetition signifies his dissatisfaction:

The nursing staff and all that were brilliant, you know what I mean. But, even they didn't really mention it, you know. They were good on what they give you, the therapy they give you, but they didn't mention, like, about you being ill or nothing like that. Whether they were, I don't know, 'appen, told to be like that, I don't know, like, really, you know. But, there were nothing ever mentioned. It were all about, like, what you were gonna have and how you ...you know, what your treatment was and things like that. And they were really good, all of 'em, like, chemo and radiotherapy, they were really, really good. But, again, there was nothing about being what you were and what were wrong wi' yer. That's what I found anyway.

Bill seems to be signalling here a form of ontological distress, captured in the distinction he makes, and everybody's apparent failure to address it, between

‘what you were’ (incurably ill) and ‘what you were gonna have’ (palliative treatment). The experience he describes is in marked contrast to the social support which Costain Schou and Hewison (1999 p. 43) found to be the ‘main activity’ some years earlier at a similar treatment centre in a different large northern city. Later in the interview, Bill talks about this again, on this occasion revealing a difference between the staff at the treatment centre and those in the oncology department:

The only thing is, like, it’s more open when you go to see the consultant, you know, when you go to see Dr. S and her staff, things are more open then. They talk about it a bit then, I must admit. It is, well, it’ll have to be hasn’t it, but it is mentioned then. They try to cheer you up. And you could think, ‘Well done,’ you know, for doing that, really.

7.3 The process of decision-making

The findings from *Experiencing Cancer* (Hughes et al 2009) show that the decision to treat older cancer patients is sometimes influenced by their age and that when patients perceive that they are being treated differently because of their age this has a negative impact on their psychological well being and on their relationship with health care professionals. In *Cancer Stories* no such influence was detected. Only one reference was made to ageist attitudes and that was to note their absence:

As far as treatment for the cancer is concerned I’ve had the best of treatment one could get at [hospital]. I’m quite satisfied with it, and I’ve never felt that because of my age, that they’re sidelining me [...] the treatment seems to be just the same as if I was 29 rather than 79, which is as it should be (Richard, colorectal cancer).

Health professionals working with this patient group appeared to conform to Kennedy’s (1992) prescription that ‘the management of cancer in older persons should be based on the individual needs of a patient and not on age alone’ (p.6). The extent to which participants’ individual *wants*, complementary to their needs as defined by healthcare practitioners, were assessed is not clear from the stories they told. In none of their accounts does it appear that ‘two fundamental issues’ identified by Fallowfield (2001 p.1144) were determined: i) participants’

own preferences about the amount and type of information they need and ii) their actual, rather than perceived desire for decision-making.

As in *Experiencing Cancer*, the process of decision-making experienced by these participants can be represented as a continuum. At one end of the continuum there is little discussion, and treatment is decided unilaterally by the medical or surgical expert. Further along the continuum there are varying degrees of discussion, consultation and collaboration, with some evidence of dissatisfaction with, or resistance to, the expert's opinions. This continuum of decision-making experiences is explored in the accounts of the *Cancer Stories* participants below.

7.3.1 The expert decides

Richard's account of his treatment exemplifies the centrality of the consultant as decision-maker:

He didn't really give me an option. He steered me into the way he thought I should go, in as much as he told me what options there were. But he thought that at my age an operation wasn't really the way to go because it was a pretty extensive operation and, er, not one to be recommended by [sic] older people. So, he decided that he would insert a stent, which he did. And, as far as going to the toilet was concerned, that was great. It solved the problem totally [...]. He then decided that chemotherapy was the way to go....(Richard, colorectal cancer).

In many of the other stories told by these participants, too, decisions about which treatments to have are made by the consultant. For most (with the exception of Bernard, see section 7.3.3 below) no dissatisfaction is expressed at this state of affairs;²⁵ there is simply deference to the perceived authority of the doctor.

For example, Alec (lung cancer) reported his 'interview' with the doctor 'telling me what'd happen, how things'd be working, to see whether it'd be either four treatments or six treatments' of palliative chemotherapy. Marjorie (colorectal

²⁵ In the NAO Cancer Patient Survey 2004 (DOH 2005, p20) 85% of patients were involved in decision making as much as they wanted (decrease of 4% since 2000 survey).

cancer) acknowledged her lack of medical knowledge as a reason for accepting what she is told: 'When they said, 'Yes, we can operate', I just thought, well, you've got to accept what they tell you. [...] I'm in your hands. You're doing what you...you know, what's right.'

Jack, too, acknowledged after the event that he had limited choice in his treatment for colorectal cancer: 'Can't do anything about it, I don't suppose. So just get on wi' it, I think, that's all. Not much more I can say about that really. But, t'only thing, I didn't want one of these bags. I don't like 'em. But what can you do?' Daniel's attitude to radiotherapy and chemotherapy treatment for his lung cancer is similarly accepting:

It's just a procedure. You just accept it. I think the whole problem is, the whole business, if you accept what is to be done for your own benefit what more do you want? There's nothing you can do. So that's how I felt about the whole procedure. It's all about acceptance.

Don regarded his prostate cancer as 'just an event' and 'just accepted it was happening' when he was taken into hospital for surgery. He referred to his radiotherapy treatment as 'the forty day trick' but said nothing about how the decision was made that he would need that treatment. Similarly he said that, 'It came that you had to have these injections,' (Zoladex) without any discussions reported, other than whether he would continue to receive his injections at the hospital or the GP surgery.

When she finally went to see the doctor about her breast lump, Doris underwent investigations which revealed that the cancer had not spread to any other organs. The treatment plan included hormone therapy to shrink her tumour, prior to surgery. The language she uses reveals subjection to authority ('I had to go...She put me on medication...Right, it's an operation'):

Then I had to go and see the oncologist and she put me on some medication [...] She put me on these tablets, Letresol, which stop me body producing oestrogen, which sort of kills off the tumours. And it did, you know, it sort of lessened 'em. And when it lessened 'em; I'm only talking to you like a layman, I don't know what I'm talking about [...] then they must have come to the stage, in July, where they said, 'Right, it's an

operation.’ Well, they told me right at the beginning that it was a mastectomy, you know, so I wasn’t bothered about that because I’d got all these months to acclimatize meself. So I just accepted it, you know, and I thought, ‘Well, it’s there. Get on wi’ it,’ you know. And so I did.

Barbara did not speak directly of decision making about treatment but alluded jokingly to her mastectomy operation; ‘There were six of us, we used to call it the one boob club.’ She spoke about all her other recent and current treatments, though, in a way which implied that it was not she who was the active decision maker, but an unnamed authority.

And then, er, after that, [mastectomy] last year, not last year, the year before, I had to go in hospital again and I had to have a kidney removed. And then, last year, I had to go in hospital again. They found out I’d a tumour in the bladder. So, I had to go in again and have the tumour removed. And I’m still going. And, as you see, they’ve just rung up and said I have to go back in again.

Decision making about John’s treatment for prostate cancer was complicated by his planned removal to a distant city and by the different views of specialists. Among two surgeons at opposite ends of the country, one discouraged surgery at the age of 65 and the other recommended it. Taking into account the views of a consultant radiotherapist as well the decision for surgery was confirmed. The impression is given of a consultative process between patient and specialists but ultimately it was the expert’s choice which prevailed.

At the time, I was just coming up to retirement, just coming to 65, and his view was that we wouldn’t operate, but we could treat it with drugs. And I explained these complications that I’d put in front of my life, that I was going to retire to L. which was near S. and he said, ‘Well, you won’t want to come all the way up here. I’ll put you in touch with one of my colleagues,’ a chap called CS who’s another urologist, well up in the field.

So, I went down and saw CS when we got there and he had a totally different view and he said, bear in mind he’s a surgeon this fella, [laughing] well, as the other chap was, to be honest, but he said, ‘Well, I don’t think RC’s up to speed here,’ he said. ‘We would operate here’.

And so I said, 'Well, fair dos.' But he said, 'Bear in mind your age. That's fine but,' he said, 'we wouldn't... if we didn't do anything now,' he said, 'when you get to 70, we wouldn't operate then because you'd be getting a bit beyond the age where we would do it.'

And he sent me to see a radiologist, as well, who was also in S. chap called B. And they were weighing the odds of radiotherapy against the operation. And, in the end, they said, 'Well, there's not much to choose between them, but we think that perhaps the right way is to have the operation.' So, probably about four or five months after I'd been down there, I had a radical prostatectomy.

Seven years later, having returned to the north of England and the care of oncologists, the decision to have radiotherapy was made apparently without consultation:

Now the PSA was quite low, wasn't completely nil, if you like, but it crept up a bit, whilst up here, until in 2004 Dr S. took me aside and said, 'I think we do have to deal with this again, with radiotherapy.' And I had 32 doses of radiotherapy.

7.3.2 Consultative decision-making

After the dramatic onset of his colorectal cancer, reported in chapter 5, Henry underwent a five week course of radiotherapy and chemotherapy to shrink the tumour before surgery. The style of decision making, in the way he tells the story, seems to be more consultative than in many other stories:

And then I finished wi' that [chemotherapy and radiotherapy] and, er, Mr. R., he'd come back by then, off his holidays, and he said, "I'd like to do another internal examina..." like, "with a telescope," he said. "But I'll have to give you anaesthetic this time cos it'll be a bit more severe than what you had before." So I had this... I went in and had this anaesthetic and I didn't know nothing. I was just talking to...I was talking to this bloke about fishing, you know, salmon fishing, and next thing I woke up in another ward [chuckling] and he'd already done it.

And he came, did Mr. R. and he said, “You know, Mr. Jameson,” he said, “the chemo,” he said, “and the radioth...it’s shrunk it so much there’s only scar tissue left,” he said. “I could operate on you this weekend if you’re agreeable.” And I said, “I am,” you know, I said, “whenever you want.” He said, “Right, I’ll see Mr. P.,” the chemo specialist, he said, “and see if it can be done.” So, Dr. P. said, “You can’t do it, because he’s another three weeks of chemo working in him yet.” So, they delayed it for three weeks and then I went in for me operation.

Recent discussions between John and a new oncologist about the dosage and frequency of hormone treatment for his prostate cancer have a more collaborative sound than the account of the decisions (reported above) to treat him with surgery and radiotherapy. There is more ‘we’ and less ‘they’:

The other bit I haven’t mentioned-I missed this bit-Zoladex. I wasn’t originally...when it started creeping up a little bit, before we came back up here, I went on to Zoladex, erm, 3 monthly implant. And that was in end of ’99, early 2000 and, er, then I talked to Dr S. about that, that over the, whatever it is, 82 days, isn’t it, it peaked. I was convinced of that. I would have hot flushes when it peaked and then not so much at the other times. And, so, we agreed I’d go on to 28 day implants, which meant I had to go and see the nurse every 28 days. And, fair dos, but then you finish up like a pin cushion. So, we went back, then, to the 82 days, or whatever it is, and I’ve been like that for the last year or more, because of that reason. Not least of which I think, one time, the injection actually caught a nerve, here, and it gets uncomfortable at times.

But, what’s this lady’s name that I saw? *Dr. B.* Oh, Dr. B. well, we talked about it, and she’s agreed to stop...we’ve stopped the Zoladex. So, I’ve been on it for a good 7 ½ years. We’re gonna give it 6 months and see whether the PSA moves at all, because the PSA’s down at nilch at the moment, which is good news, it’s great news, and has been for a while. So, we’ll see if it stays that way and then...

Similarly, when Jack’s cancer spread to his liver, and given his general state of health, decisions about treatment were not made independently by the

consultants. The options were explained but the decision was left with him. Jack's wife Florence explained:

The other worry, a few months ago was, big decision to make, the tumors have gone to his liver and there was a possibility he was going to be operated on [...]. Mr B. (surgeon) went over to see him. He explained various aspects of it and they were...sent him away to think about it. He said, 'I can operate. I will operate, if you want me to,' he said. 'But bear in mind your age, the difficulties you had after your last operation,'- because he had a bit of a heart attack after the bowel operation, got a few breathing difficulties-he said, 'just bearing all that in mind,' he said, 'go away and think about it.' I think he was thinking, Mr. B. he's not really fit for another major op, you know. And I think Jack agreed. I think you'd made your mind up before we got home hadn't you that day *yeh[JF]* So, he decided not to go ahead with...that's why he's continuing with chemotherapy of course.

7.3.3 Resistance to expert opinion

In Jean's stories of her life and her illnesses there is a repeated refrain of her negotiating, bartering, combating health professionals in apparent refusal to defer to their authority and status. In this extract she situates herself as someone making sacrifice, for the benefit of future generations of patients, as she makes the decision to endure the painful side-effects of a trial drug for lung cancer, despite having been offered by the consultant the chance to stop taking it:

But there's another generation comin' up, so I'm doin' me bit for them. And when it had grown that time [...] Dr. B. said, 'It's grown', she says 'do you want to come off it?'. She said, 'I'll give you a week to think about it.' I said, 'No, I won't come off it. I said I would carry on and I will carry on.' And then she rang me during't week and she said, 'I think you're doing right, stopping on it.' And I thought, 'No, there's another generation.'

Michael was compliant with some decisions made on his behalf: 'They said, "You'll have to have an operation on your prostate."' And later, as his PSA was

rising: 'She said, "We'll have to sort this out, there's problems here." Fair enough.' But he was resistant to having follow-up in the hospital where he underwent surgery as it is further from his home. And, at the time of the interview, he was just coming round to the recommendation of radiotherapy, having earlier refused it because he doesn't want to go to the hospital every day:

I'll probably finish up on the treatment they want to give me. It's er Monday to Friday, every day for seven weeks, for ten minutes, you know, but, er, up to now, I said, it's bad enough having to come once every three months and twelve months. I don't think I'd like to come every day.

Bernard (prostate cancer) revealed himself as a knowledgeable patient who seeks out information and sometimes takes a critical attitude to the opinions and prescriptions of specialists:

I had the biopsy and they said that I had prostate cancer, which was considered to be, sort of, mid-range on the Gleason score etc and they decided that I should go and see the oncologist, who was part of the team, Dr A at [named hospital], and in the interim they prescribed some tablets.

Well, I read Patient's Notes. I don't know how many people read Patient Notes, not very many I don't think, and I looked at this, and... I've got an uneven heart beat and it said that it could... one of the side effects, the possible side effects, was uneven heart beat etc.. So, I rang the urology department at X and the nurse there, the sister, the nursing sister, talked to the urologist and the result was that I needn't take the tablets if I didn't want to. Which I considered was very unsatisfactory.

But, however, I didn't take them and just let things toddle on. I went to see Dr. A. I've always found the oncology staff remarkably easy to talk to, and very civilized. And, as a result of what he said...well, I told him to start with, 'Look, if I've got something in my body that shouldn't be there, I want to get rid of it. The only way to get rid of it appears to be radiotherapy. Now, what are the pros and cons,' you see? He presented a whole lot of symptoms, which were more in the nature of probable side effects rather than possible side effects, which wasn't very comforting

LIVING WITH CANCER IN OLD AGE:
A QUALITATIVE SYSTEMATIC REVIEW AND A NARRATIVE INQUIRY

really. And, really, he was clearly in favour of 'watchful waiting,' which I wasn't.

7.4 The effects of treatment

Cancer is a complex disease and it is apparent from the experiences recounted by the participants in this study that a multi-level approach to treatment is often required (Chau & Cunningham, 2009). The range of treatments undergone by each individual can be seen in Table 7.1 (p. 171).

Participants' spontaneous comments about the effectiveness of treatment (they were not asked about this directly) range from reports of partial success (James) through expressions of cautious hopes (Richard) to statements of satisfaction that the treatment seems to be stopping the cancer getting any worse (Bill, Daniel-both know that 'nothing can be done'). Sometimes one treatment is seen to be successful while the outcome of another is awaited: for Richard, surgery completely solved the problem of bowel obstruction but the effects of chemotherapy on the tumour remained to be seen. Barbara has completed treatment for breast cancer but is still undergoing chemotherapy for bladder cancer. Most patients did not report symptom burden from the cancer itself.

The experiential world of the participants is revealed more extensively in their stories of the side-effects of treatment, rather than in their accounts of what they know about the impact of treatments on their tumours. Most of the treatment side-effects reported are transient. They may be difficult, even, in Don's word, 'nasty', but mostly are portrayed as manageable. Ultimately they wear off and the overall assessment is sometimes that it was worth it. For one participant (John) side-effects were persistent.

There was some indication that participants were informed about the nature of possible side-effects or the likelihood of their occurrence. Henry was told 'we're going to make you feel worse before you feel better'; Bernard was advised against radiotherapy because of possible side-effects; John reported that the possibility of incontinence and of impotence were discussed with him and his

wife.²⁶ In the following sections, I summarise participants' stories of treatment side-effects.

²⁶ In the NAO Cancer Patient Survey 2004 (DOH 2005, p20) 16% of those over 80 reported that side-effects of treatment were not discussed, compared with 6% of younger patients.

Table 7.1 Treatments experienced by each participant

Breast Cancer	Colorectal/Intestinal Cancer	Lung Cancer	Prostate Cancer
<p>Anne Pre-operative hormone therapy; surgery; post-operative radiotherapy; continuing hormone therapy</p> <p>Doris Pre-operative hormone therapy; surgery; continuing hormone therapy</p> <p>Barbara Surgery; post-operative radiotherapy; chemotherapy for concurrent bladder cancer</p> <p>Maria Surgery; post-operative radiotherapy</p> <p>Pamela Surgery; radiotherapy</p>	<p>James Surgery; multikinase inhibitor</p> <p>Henry Pre-and post-operative chemotherapy and radiotherapy; surgery; post-operative chemotherapy</p> <p>Marjorie Surgery; chemotherapy</p> <p>Jack Surgery; chemotherapy</p> <p>Richard Surgery; chemotherapy</p>	<p>Alec Chemotherapy</p> <p>Daniel Chemotherapy</p> <p>Jean Chemotherapy; radiotherapy; epidermal growth factor inhibitor</p> <p>Bill Chemotherapy; radiotherapy</p> <p>Reggie Radiotherapy</p>	<p>Clive Radiotherapy; hormone therapy</p> <p>Bernard Non-specified medical treatments pre-surgery; surgery</p> <p>Michael Surgery; radiotherapy recommended</p> <p>Don Surgery; radiotherapy; hormone therapy</p> <p>John Surgery; radiotherapy; hormone therapy</p>

7.4.1 The side-effects of surgery

Five of the fourteen participants who underwent surgical removal of their cancer experienced some side-effects of the operation. Some side-effects of surgery were transient, and although predictable, could be surprising and uncomfortable (Bernard's incontinence) or painful (Henry's rectal sinus).

Bernard described his experience with characteristic attention to narrative detail:

I'd been hanging about waiting for this TURP operation in six weeks and it didn't come. Finally, I had it on the 21st of April. How successful it's been, of course, I don't know. It was not an experience I wish to go through again. Apparently...when you sign the consent form, of course, they go through things and they point out various things that might happen and one of them was incontinence. They mentioned... I think it was about 3 percent, certainly very low and...I was aware of that because of things I'd read before, that there was a very small possibility... BUT, I BECAME INCONTINENT....devastating to me. That was the last thing I wanted. I'd absolutely nil control. Made a mess of things, really did, in the waterworks department. That's all it was, not bowel incontinence, but I'd definitely no control. And that to me was totally unexpected. Well, no I can't say totally, can I, in view of what I've just said, but I thought I was one of the unlucky ones you see, one of the 3%.

And the nursing staff in the ward were, well, they weren't, it's not true to say they were almost blasé about it, but it was certainly treated as something by no means unusual. Now if somebody had said to me that that might happen I would have been prepared for it and I wouldn't have been, well I can't say I was distressed because I wasn't tearful or anything like that, but I was very upset. I'm too fastidious really [chuckles] to be incontinent. But they were very good and they said, 'Oh, well it would clear up in a few days in all probability.' But, of course, I was home before that cleared up and sure enough in two or three days I virtually got full control back. But it was a bit of a shock, at 78 years old, to be put into nappies [chuckling] you know, not at all what I'd expected. People can

LIVING WITH CANCER IN OLD AGE:
A QUALITATIVE SYSTEMATIC REVIEW AND A NARRATIVE INQUIRY
cope with anything, almost, if they know what's likely to come and that
was so with me.

Henry gave an apparently contradictory account of the pain he experienced from a post-surgical rectal sinus, again, a predictable side-effect of surgery. In this extract he reports intense pain, but at the same time indicates that he received analgesic medicine which was effective. Really effective pain control, however, is achieved by calculating the dosage and frequency of administration of analgesic medication such that the intensity of pain described here does not arise.

I mean, I were full of morphine and this thing at the back, where I was stitched at the back, I had this big dressing on. When I used to go for a shower it all used to come out and, ohhh! it used to make me sick nearly, you know. And the pain. I couldn't describe it. I were taking pain killers, you know. I had pain killers, everything were alright as far as that goes, they wouldn't let you have pain, you know.

Other side-effects of surgery could also be predictable but have more serious long-term consequences. For one participant, John, the effects of radical prostatectomy (compounded by radiotherapy) were permanent urinary incontinence and impotence. Initially, the incontinence which followed his operation was manageable.

I had a fair bit of trouble with the catheter. It kept choking up, and in consequence the district nurse came in and dealt with that, and I never went back because they'd taken the catheter out by then and said, 'Well, probably not worth coming back.' And I missed out, this is me, my version, on physio afterwards, which I think probably was a mistake, I think. Now, since then I've had a fair bit of incontinence. Perfectly livable at that stage, it wasn't too dramatic. It's not so bad if you're lying down. But if you're upright, that is the time. And if I go out walking it does create a reasonable amount of leakage then. But I could live with that. I acquired a bicycle and I was fine on a bike. I could ride round on the bike and I did that and for those years down there [living in the South of England] that was my mode of transport and that was fine.

When John returned to the North West some years later he required radiotherapy to control his cancer. The impact of radiotherapy on his incontinence is reported in section 7.4.3 below.

Sometimes there were unpredictable side-effects of surgery which also had potentially serious consequences. Jack experienced a heart attack after his operation for bowel cancer which left him unfit for further surgery when the cancer spread to his liver. In his wife Florence's words:

There was a possibility he was going to be operated on at [hospital], Mr. B [surgeon] went over to see him. He explained various aspects of it and they sent him away to think about it. He said, 'I can operate. I will operate, if you want me to,' he said. 'But bear in mind your age, the difficulties you had after your last operation,' because he had a bit of a heart attack after the bowel operation, got a few breathing difficulties. He said, 'Just bearing all that in mind,' he said, 'go away and think about it.' I think he was thinking, Mr. B, he's not really fit for another major op, you know, and I think J. agreed [...] So, he decided not to go ahead with it.

7.4.2 The side-effects of chemotherapy

All nine patients who underwent chemotherapy reported or alluded to side-effects, including anorexia (Barbara, Daniel), nausea (Jack, Henry-both still on treatment), weakness, lethargy, fatigue (Barbara, Richard, Alec) and hair loss (Jean). There was wide variation in their intensity and where the individual had received radiotherapy as well the side-effects of chemotherapy were perceived to be less severe by comparison. Henry, for example, felt 'rotten', experiencing nausea and weakness from the combined effects of preoperative chemotherapy and radiotherapy. But, he concludes that, 'radiotherapy seemed to do me worse than ever':

They told me at the hospital, when I were going to have this radio and chemotherapy 'We're going to have to make you poorly to make you better'. Which they did. And I went for chemo every day for five weeks and radiotherapy every day for five weeks, same day. I'd have chemo twice a day, morning and night, and the radiotherapy sometime during the day. Now they got on to it straight away. I was sent in more or less straight.

They found this thing, and I was sent in and they started treating me. And I used to come up, they'd take me in a car and fetch me back from [hospital]. Absolutely marvelous the way they looked after me. And I used to come home and I felt that rotten I used to just kick me shoes off and go and lie on me bed for a couple of hours till I come round. Because I couldn't describe the feeling. It's like a sickly... you feel... it's like nausea, I couldn't describe it. And I felt that weak and with that...radiotherapy seemed to do me worse than ever.

Henry's post-surgical treatment with chemotherapy was different from the preoperative treatment and had correspondingly more intense effects:

After I'd had me operation they told me... this Dr. S. I went to see him, he said, 'well,' he said, 'we've done trials and,' he said, 'we've found out that if you have this dose of chemo after...you know, it'll be a lot stronger than what you had before but,' he said, 'we do it after your operation,' he said, 'we've found out it's better than waiting six month and having a blood test and if there's owt wrong we've lost six month, if we wait,' he said. 'So, you don't need to have it if you don't want but if you want to have it you'll have to sign,' you know. So, I signed for this chemo and I'm in't midst of it now. I think I've had about three months now, is it, or summat like that. So another...I think it'll be March when I finish on this chemo which is....I have it twice a day, you know, which is a fair lot, and it knocks me sick, but I'm getting used to it, I think. I have fourteen days on with it and seven days off. And I look forward to them...I....not so long and I'll be off again. And there's always somebody coming, like me grandchildren and everything, you know, they come round and while they're here I'm not...sometimes I feel nauseated and feel sick and I feel depressed and when they come, it goes. You know, I'm dwelling on something else.

Barbara underwent chemotherapy for the bladder cancer which followed her breast cancer (treated with surgery and radiotherapy) and seemed untroubled by the attendant loss of appetite:

I did have to go for treatment for chemotherapy. For six weeks I had to go to have chemotherapy pumped into the bladder. It wasn't so bad, but I've never been able to eat a meal since. If you ask me what I'm having today

for a meal, it's ham sandwich. And what am I having tonight? A ham sandwich. I did have a meal at Christmas, my daughter made me eat. But, never cooked a meal since. But I still don't lose any weight!

Daniel was phlegmatic about the loss of taste and his lack of desire for foods he would normally enjoy, approaching these effects of treatment with the same fatalism he brought to the whole experience of illness:

Well, I must admit that from Emily's point of view [his wife] it's been a bit difficult in so far as my choice of food has been at great variance to what my normality has been. I've normally been able to eat anything, no problem. But since I've been on chemo I just couldn't face certain things, things I would love to eat before, but for some inexplicable reason ...

-What sort of things?

Well, at the moment I'm off eggs. Initially I was off bread, and potatoes [wife chuckling]. Vegetables, I would normally eat a lot of. I haven't been doing, not lately. It'll come back [...] everything comes back bit by bit. It's just something one has to accept and does accept because you know what's going to happen, you're going to get normal.

Several participants had expected to have side-effects and were surprised at their relative lack of severity compared with their expectations. Richard, for example, reported that:

I've just completed me fourth session of chemotherapy which, whilst it's not particularly pleasant, is not as bad as I expected it to be because you do hear people who've been through this before having numerous side effects and the only real side effect I've had is feeling lethargic.

Marjorie's expectations of side-effects, too, were unrealised:

When they told me about chemo, what could happen, I did panic a bit [...] but none of that's happened. So if I'd have kept worrying I'd have been worrying for nothing.

In keeping with her stream of consciousness storytelling style Jean did not refer directly to her own chemotherapy treatment but, off the record, talked about

her wig, from which it may be inferred that she experienced hair loss as a result of chemotherapy.

7.4.3 The side-effects of radiotherapy

Of the 12 participants who underwent radiotherapy treatment nine reported side effects. There is variety in the intensity of expression used to describe side-effects of radiotherapy and the detail in which participants reported them. There is an apparent gradient in the reporting moving from mild to severe.

Maria, unusually, felt well during her 12 radiotherapy sessions:

I felt fantastic I must tell you, all the time I were 'avin me radium I felt fantastic. And t'drivers, bringing me 'ome used to say, 'My dad had that love and he were always asleep, are you alright?' I said, 'I'm fine.' it's after, it's after [ie fatigue].

For Jean, despite having had burnt lips, 'It's nothing, isn't radiotherapy'. For Pamela it was, simply, 'tiring'; for Reggie, it was 'a bit of a rough job'; while for Don it was 'nasty'.

Clive spoke of being confined to his upstairs bedroom with diarrhoea for three months while undergoing radiotherapy:

It was horrible, really, because if I ate anything, you see, if I ate perhaps a sandwich or a biscuit, even, it would..., I'd have to go after straightaway, through the radiotherapy. And it was blinking awful, you know. And after a time, when I got a little better, I started to feel that I wasn't hungry. Alice [wife] kind of give me stuff but I wasn't eating at all, then. I suppose it was because of the radiotherapy. But it was really terrible, it was. Because I thought, in fact..., I didn't realize..., I thought, when I had the radiotherapy you don't feel anything on that; it's not like chemo, or, you know, not at all. I thought, 'Oh, this is pretty good. I don't mind going down to [hospital] and back and having it done.' But after I come back, that's when it started, upstairs, you know, that was when the trouble started and it was really bad.

Like Henry (section 7.4.2) Bill underwent both chemotherapy and radiotherapy, and found the side-effects of radiotherapy to be the worse of the two, though the ill-effects were transient:

I weren't too bad with chemo. But that radiotherapy...I started off, must have been like a few... a month or so after I'd had it and I went to t'doctors. Oooh, I'd pains in my stomach! And t'doctor says, 'What it'll be is,' he said, is that they put a mark on you don't they? like where to send it to, the ray, and he said, 'If it's veered a bit off that,' which, he said, it can do, he said it can affect other muscles, like, whatever it is that are near there. 'And that's what's making you ill.' So, he gave me some medicine [...] and it did cure...in the end it were about a few weeks of a job, but it did go. So, it must have been that, really. But, by gum, it were every night. It were like stomach ache, you know. But, it's been alright since.

John suffered the most prolonged effects from radiotherapy, which both affected his rectum and worsened the urinary incontinence which had been the effect of radical prostatectomy (section 7.4.1).

The PSA [prostate specific antigen] was quite low, wasn't completely nil, if you like, but it crept up a bit until, in 2004, Dr A. took me on one side and said, 'I think we do have to deal with this, again, with radiotherapy. And I had 32 doses of radiotherapy, which didn't help with the incontinence by any stretch of the imagination [kind of a chuckle that I don't know how to describe] He did warn me, in fairness, there's no doubt about that. And it didn't help the rear end, either, you know. The rectum was a bit of a mess, to be honest. And that really covers it. That's where I am now, with quite, I suppose one could say, serious incontinence.

Now, I've had support from the incontinence service. They do supply the kit. I'm working on them, but they still supply me female kit when I know you can get male kit. And we have tried various bits of kit where people are developing it, you know, fit over the penis and supposed to collect it from there. And, I'm afraid that when you've had radiotherapy and the operation...,because ever since then I've never had an erection. And for all after the operation [surgeon] tried Viagra and all these things none of

it ever achieved that. So, in consequence you can't fit something on the penis because it won't stay there. So, that piece of kit which, in fairness, was under development, and I was prepared to put my few words into, didn't work. And I think they're struggling with that, still. But you can get male pads, which might be better. But they need to be very absorbent for my part [laugh]. I do leak a lot. If I measure it on an average day I suppose I'm talking half to three quarters of a litre. So, you know, you're talking about 3 or 4 good pads a day which means you have to plan your days around certain stops you wish to make, especially if you're on your feet and up and moving [...] So, that's my main problem at the moment.

7.4.4 The side-effects of other treatments

Participants reported a range of side-effects from hormone treatments for breast (Anne) and prostate cancer (John), from a multikinase inhibitor for gastric cancer (James) and from an epidermal growth factor inhibitor for lung cancer (Jean). In most cases the side-effects were temporary (Anne, John) and were sometimes tolerated in the light of other benefits brought by the drug (James) or of determination to continue with treatment (Jean).

Anne found that the hormone treatment prescribed before she finally decided to have surgery burned the inside of her mouth:

I just found this lump and I showed it my daughter. My daughter's a nurse and, er, she says...as I said, I went to the doctor's and he sent me to hospital so and then I had tests and that and he said, It's cancer.' He put me on different tablets. The last tablets he put me on, he said they were new ones and there was only another woman and me was on them, but they were terrible. They burned the inside of your mouth, you know, and I didn't like them at all. So, I was only on them about a couple or three weeks and he took them off me and then I went in for the operation.

James reported experiencing some of the common side-effects of the multikinase inhibitor Sutent (mouth ulcers and sore feet) but, for him, they almost paled into insignificance in the light of his overall evaluation of the beneficial effects of the drug:

The side effects are in my case mouth ulcers and, er, so that was back to children's food and very, very sore feet . But after two months of tablets and a month in between each course, or two weeks in between each course making a total of twelve weeks, erm, the cancer has reduced by, erm, almost a half in some cases and one of the cancers has disappeared completely.

I was bringing a lot of sputum up from my lungs [but] since I've been on these tablets, Sutent, that's cleared up. I've none at all. I don't cough at all now. Everything, everything about...they talk about this being a wonder drug, this Sutent. It certainly is in my case. Up to now it's cleared up one of the cancers, that was a fluid in my stomach, there were these small cancer, what do you call 'em modules or I don't know the term for them but they've gone completely. They've gone completely and all the others have reduced. It's remarkable, it really is. I'd like to think it continues [chuckle].

Finally, Jean, with characteristic resilience, spoke of her tolerance of the side-effects of Tarceva and her determination to continue with the treatment :

There's something wrong with it because of the side effects it produces. I mean once I were covered in boils. I were just covered all, from head to foot, in boils. And that were really painful. And I used to think, then, 'I'll give up to it, I'll stop taking it,' you know. And then I'd stamp me stick, like this, and I'd just think [spoken through gritted teeth] 'Put up wi' it, put up wi' it.' And, er, but I wouldn't give up to it. No, I've never given up to anything in me life, I'm not gonna start now.

7.5 Summary

In this chapter I have presented three themes from the stories of treatment told by participants in *Cancer Stories*, showing what they said about their satisfaction with their overall treatment, about their involvement in decision making about treatment and about the physical effects of various treatments.

Just under half of the participants spontaneously expressed satisfaction, sometimes in strong terms, with their overall treatment. A few dissatisfactions

were voiced, relating to patient-provider interactions (Bill, Henry, Pamela) or to discharge follow-up (Pamela).

With regard to involvement in decisions about treatment, findings presented here are broadly consistent with empirical evidence which suggests that older people with cancer may prefer to play a limited role in decision-making and to defer to their physician's expertise (Arora & McHorney, 2000; Benbassat et al 1998; Blanchard et al 1988; Degner & Sloan, 1992; Degner et al 1997, Elkin et al 2007; Rothenbacher et al 1997). Elkin et al (2007), for example, found that 52% of their study population of 73 individuals aged 70-89 with metastatic colorectal cancer preferred to delegate all treatment decisions to their physician. In younger age groups more active or collaborative roles may be preferred. Bruera et al (2002) found that 67% of women with breast cancer, with a mean age of 62 years, preferred shared decision making with regard to treatment choice.

Preference for involvement and control of decision-making does vary even within older age groups, however (Elkin et al 1997). In a survey of 101 men with prostate cancer, with a mean age of 70, mostly married and well-educated, Wong et al (2000) found that more than 60% of the men wanted to share decision making about treatment with their physician. In addition, over 70% wanted detailed information at all stages of the illness. In *Cancer Stories* the better educated participants were more likely to question aspects of physician decision-making: Bernard expressed his dissatisfaction with 'watchful waiting'; John insisted on following up the PSA result from his privately funded prostate screening test, against the indifference of his NHS general practitioner; Don insisted on a Do Not Resuscitate (DNR) order when he was in hospital and refused further radiotherapy against the preferences of his consultant oncologist ('she doesn't agree with me about one or two things'). In contrast, participants with a lower level of education and socio-economic status were more passive. Clive, for example, acknowledged that he 'doesn't ask enough questions' and was consequently in the dark about the extent of his disease and the nature of proposed treatment. Michael's resistance to his physician's recommendation for radiotherapy took the form of a simple refusal.

Numerous studies draw attention to potential discrepancies between desired and actual roles in decision making about treatment and recommend that efforts are made by clinicians to minimise the disparity between the two (Davidson et al 1999; Degner et al 1997; Elkin et al 2007). As already noted, there is no evidence in the stories told by participants in this study that their preferences had been elicited. With few exceptions, participants accepted the treatments recommended by their healthcare providers, tolerating a range of unpleasant side-effects, in the interests of attaining a cure, or of slowing down the progress of their disease.

In the next chapter I move from analysis of the cancer stories to consider how participants' illness narratives may be interpreted in the light of what they told of their life stories.

CHAPTER 8

'CANCER STORIES': ANALYSIS AND INTERPRETATION OF FINDINGS (4)

SITUATING SELF IN A LIFE WITH CANCER

8.1 Introduction

The end point of the illness trajectory for people with cancer, in Corbin and Strauss's (1988) schema, is death. In the twenty years or so since the publication of their book, treatment for cancer has become more effective. Hence, there is likely, for many people with cancer, to be a post-treatment phase of the illness trajectory, of varying length, which is characterised by a continuing life rather than by a rapid decline to death (Sinding & Gray, 2005). This new reality has resulted in research studies and literature focused on what is called 'survivorship' (Aziz, 2002; DOH, 2007; Feuerstein, 2007). In relation to the interview data generated for this study I call this phase of the illness trajectory 'situating self in a life with cancer.'

In this chapter I draw on the wider life stories told by participants, going beyond the specific illness narratives of the 'cancer stories,' to interpret their experiences of cancer in the context of their overall biography. In addition, as explained in Chapter 5, I interrogated the life story data from a more etic perspective using analytic questions suggested by Frank (2008): 'What other stories are people caught up in?' and 'What differences depend on being caught up in those stories?'. Exploring the data in the light of 'grand narratives' (Davey and Seale 2002) and the 'lens of culture' (McCormack, 2004) further helped to situate and interpret the private experiences reported by these participants in a broader social context.

8.2 Characteristics of the 'situated self'

The overriding features of situating self in life with cancer among the participants in this study are hope and hardiness, together forming a kind of

resilience (Hughes et al. 2009) which appears to be psychologically protective and which fosters a determination to continue living positively. Hope is revealed both in specific and general terms (Hammer et al 2009): as a desire for successful curative treatment (James, Richard, Henry, Margaret) and for the relief of symptoms (Bernard, John) but also as an orientation to a positive outlook on life which is maintained even in the face of suffering.²⁷

Hardiness is the ability to withstand adversity. It is closely linked to resilience, but, in the view of some authors, differs in that ‘resilience results in an improved or enhanced adaptive outcome,’ whereas, ‘hardiness allows individuals to endure significant adversity but there is not necessarily a positive change in outcome’ (Earvolino-Ramirez, 2007 p 80). Felten (2000) shares this view. Hardiness may, then, be considered a necessary but insufficient condition for resilience. Bonanno (2004) presents hardiness as one of four possible ‘pathways’ to resilience. Wallace et al (2001) suggest that hardiness offers an ‘internal personality reserve’ which produces resilience when combined with the ‘external reserve’ of social support, though the direction of influence between the two is open to different interpretations in their study.

In *Cancer Stories*, hardiness is seen in the robust characters of the participants, a robustness which underpins their adaptive responses to the adversities of living with cancer. In this narrative study, which did not seek to measure predetermined variables, hardiness is used as a term which is descriptive of the participants’ characters, as perceived by the interviewer/analyst in response to their presentation of themselves in the telling of their life stories. It is thus an impressionistic use of the term which cannot easily be related to the theoretical constructs of hardiness (commitment, challenge, control) proposed by Antonovsky (1979) which underpin psychological research (Bonanno, 2004; Lambert et al 2003; Wallace et al 2001).

Resilience, ‘the ability to bounce back or cope successfully despite substantial adversity’ (Rutter, 1985), is distinguished from hardiness also by being redefined

²⁷ It is characteristic of this study population to make light of their suffering in comparison with that of others. This was also a common finding in the studies reviewed by Hughes et al (2009). The phenomenon is described in the psychological literature as ‘downward comparison’ (Wills, 1981).

in contemporary literature as a dynamic, modifiable process (Luthar, Cicchetti & Becker 2000) rather than as a personality trait. In Earvolino-Ramirez' (2007) concept analysis, resilience is presented with six 'defining attributes' (Box 8.1).

Box 8.1 Defining attributes of resilience (Earvolino-Ramirez, 2007)

Rebounding/Reintegration

Bouncing back and moving on in life after adversity

Readiness to 'get back to normal'

High Expectancy/Self-Determination

Sense of purpose and achievement in life

Not being overwhelmed by feelings of hopelessness or extreme challenge

Positive Relationships/Social Support

Meaningful relations with at least one peer or family member

Flexibility

The essence of adaptability

Being cooperative, amiable, tolerant.

Sense of Humour

Able to make light of adversity, enhance coping mechanisms, moderate intensity of emotional reactions

Self-Esteem/Self-Efficacy

Underpinning adaptive or maladaptive responses ('why some people snap and others snap back')

Present innately and from mastery of previous experiences.

Each of these defining attributes of resilience may be seen in the stories told of their life and cancer experience by participants in this study. Many examples of such responses will be reported in the rest of this chapter and will support Collins & Smyer's (2005) contention that 'despite the losses associated with ageing, older adults are surprisingly resilient to life stress' (p475).

The nature of hope, hardiness and resilience among the research participants is influenced by the type and stage of the cancer as well as by former and current life events. For Bernard and Richard, hope resides principally in the desired curative outcome of their treatments for prostate cancer (surgery for Bernard; surgery and chemotherapy for Richard). For three participants with lung cancer who know that they have advanced, incurable disease (Alec, Bill, Daniel) hopefulness is coloured by resignation, a realisation that the best that can be

hoped for is that the palliative treatments they have undergone will slow down the progress of their cancer. Reggie, also with advanced lung cancer, expresses hope in his attitude of purposeful activity, both giving his time to help his family and neighbours in tasks of daily living²⁸ and in pursuing creative hobbies ‘to take his mind off the cancer.’ Jean’s response to her lung cancer is to persist with active treatment through participation in a clinical trial, despite unwanted side-effects, more in the hope that others will benefit than in the interests of her own survival.

Michael, Clive and Don, all with advancing prostate cancer, seem to express a kind of hopefulness in simply carrying on with their daily life, apparently unaffected by their progressive disease. Clive describes feeling concerned that the consultant has indicated he will need to have injections, because he thinks, though hasn’t been told, that means his cancer has ‘come back.’ And he recognises that his habit of not asking questions has left him a bit in the dark about what is happening. He does not appear to be anxious but he returns repeatedly in the interview to what he sees as his lack of understanding about his illness.²⁹ But his daily life continues apparently unaffected. Michael appears unconcerned that the recommendation from his consultant that he now needs radiotherapy probably means that his disease is advancing. He is more concerned with the inconvenience to him of daily attendance at hospital to undergo the treatment. Don knows for sure that his disease is advancing but he is ‘not losing any sleep over it’ and is purposefully ploughing ahead with business plans.

Sometimes hopefulness is revealed more explicitly as a fatalistic resignation, typically a view that you simply have to accept what has happened (Daniel, Jack) and ‘get on with it’ (Doris). ‘Life must go on’ according to Barbara (81) who is itching to ‘get back to work.’ Wagnild & Young (1990) found that such attitudes of ‘equanimity’ and ‘perseverance’ characterised older women who

²⁸ Compare Pentz’ (2005, p 10) report of his participant ‘Jack’ who ‘even as his health declined continued to do what he could for himself and others.’

²⁹ This is one of two occasions in the interviews where I felt compelled to step, temporarily, out of my role as researcher and enter my role of nurse. (The other was in giving empathetic support to John in giving him ‘permission’ to feel that his incontinence was, indeed, severe and that he could legitimately regard it as a major problem deserving of health professionals’ attention). At the end of the interview I made some suggestions about how Clive might question his consultant so as to get better understanding of his condition.

had experienced major loss in life. Anne, alone among the participants in this study, expresses religious faith as the underpinning of her hopeful attitude

I've put my trust in God [tears breaking into and through voice] I don't know whether you believe in God or not but he just said he would look after me and so he did, for so far, and, like I say, I can't complain because I've got a lot years that I didn't think I would have.

It is faith in human relationships which nurtures a hopeful attitude in Henry. He singles out the psychological support of one of his friends as among the most helpful of his experience³⁰:

She come down when she knew what were wrong wi' me, as I'd been diagnosed wi' cancer. She were upset, you know, she cried when she come in. And she said, 'I'm gonna write summat down and you'll be alright.' And that's what she wrote for me [shows me a list written as bullet points on the back of an envelope] and I look at it, you know. You know, it's grand. That did me more good than owt, you know, looking at that thing every day [...] She said, 'Well, look at it this way.' And she wrote this down: 'They've found it. It's treatable. They're going to shrink it. And then: operation, quick appointments, short term inconvenience, isolated, nowhere else' - which they told me, the cancer was just in one place- 'Soon back to being as fit as a fiddle. Lots of family and friends support in the meantime.' Now, that's what she wrote for me and it did me good, too, when I read it. Now it does, you know.

8.3 Resilience

8.3.1 Influence of life-events on resilience

Each of the participants in this study expressed attitudes to their life with cancer which could be described as resilient (Hughes et al 2009; Earvolino-Ramirez, 2007; Felten, 2000; Moloney, 1995; Nygren et al 2007; Wagnild & Young, 1990). One way to interpret this trait is to see their current character, personality, attitudes and behaviour as being forged by their life experiences,

³⁰ See Moloney 1995 p106, whose participants 'gave examples of others who had helped them to be strong.'

including episodes of hardship³¹. Seen in this light, both former and current life events can be seen to influence the response to living with cancer. A long life is rarely free of troubles (Frank's (2008) starting point for a 'story') and stories of divorce, illness, domestic violence, death and bereavement appear in the stories collected for this study. Jean and Reggie had both been divorced, in traumatic circumstances, though Reggie maintained amicable relationships with his wife (who telephoned, to ask after his welfare, during the interview). Michael, Don, Anne, Maria, Doris, Barbara, James and Henry had all been bereaved of their spouses (between 1-20 years ago). As already noted (p. 131) one of Jean's daughters died a violent death in her early twenties and she had suffered years of physical and emotional violence at the hands of her first husband. Maria's daughter had died at the age of 28 of a brain tumour. Michael's adult son committed suicide following separation from his wife. Pamela had lost two of her five sons, the eldest at age 16 from an accident and the second eldest at age 21 following a leg amputation for cancer.

Resilience is formed also by more mundane experience, simply by experiencing the privations more typical of less affluent times (Henry), by the necessity for extremely hard work (James, Barbara), by surviving multiple illnesses, including other cancers, (Reggie, Anne, Jean), or by the persistence of caring responsibilities into advanced age (Maria).³²

Henry was born in 1932, one of five children, and the beginning summary of his life into young adulthood is characterised by hints at relative poverty and lack of choice:

Times were fairly hard. And I can remember like me mother say...I was in bed sixteen week with her cos she had a, you know, what they call a white leg, like a clot and when the doctor came, like, the bill was thirty odd pound, I couldn't remember, like, she said it was a lot of money, then, cos

³¹ Compare Felten's account of resilient women aged 85 and older (2000 p10): 'All the women described hardship earlier in their lives, including challenges associated with racism, religious or ethnic discrimination, divorce, the Great Depression, death of a husband, domestic violence, and the effects of war.'

³² Felten (2000) identified helping others as a characteristic of resilient older adults.

me dad he'd only be on about £8 a week or summat like that,³³ I don't know. And, er, me childhood like it...we grew up and, er, I went to the school when I were five and, er, left school when I was fourteen and I started work on a farm, which there were nothing else, you didn't know owt else then, like, it were either farm work or goin wi me dad to Leyland to learn brick...and I didn't want to work with him, like, really, because [chuckling] you know, he were a bit of a gangmaster, like, you know, when we were at home, like, he were a bit strict. And, er, I worked for this farm for six years I worked there. And me first wage were twenty eight shilling for the week. And, er, like it weren' a lot of money but, you know, I used to tip it up to me mum. She used to gi me two shillin', like, for spending money. This is going back to the old currency, now. And, er, after a while I left there and I went to another job which I were forced into, really, because you had to learn to do everything wi tractors and everything to plough to get on top money and the top wage were six pound a week.

Henry also exemplifies a physical resilience which comes from life of hard manual work :

When you went for grain to these warehouses, if you hadn't a bulk wagon you used to carry it in two hundredweight sacks [...] and you had to carry them in your arm off a chute and load 'em into your wagon, 'cos they'd got it at bulk price, if you'd got it in two hundredweight bags, and, er, you know, like, you got a strong back. You used to wear some shoes out, and some shirts and jackets, you know, it were a rough job. But I stuck it because I had to do, you know.

James, born in 1933, also left school at 14 and apart from two seven week periods when his life was aimless-one immediately following school 'dawdling', in his mother's view, on his grandparent's farm in Ireland and one spell following the army doing bar work in Blackpool-his whole life was characterised by extremely hard work. He became an apprentice armature winder aged 14, 'winding big motors for diesel electric trains,' and worked for 40 years in the electrical engineering industry, sometimes for 12 hours a day, 7 days a week and

³³ My marginal note in the transcript questions the accuracy of this recollection, based on my own experience: 'As much as that? I earned £11 per week in 1972.'

while also running, with his wife, an off-licence shop. During the last few years of his working life James also nursed his wife at home with breast cancer until her death. He retired from work early at age 57. Ten years later he moved in with his new partner and at age 70 the first symptoms of his cancer appeared.

Barbara was born in 1928, one of seven children, and tells a story of her childhood, in tantalisingly little detail, which provokes a kind of internal horror in my mind³⁴ as I compare her experience with what I see as the ‘normality’ and security of my own childhood. In particular, I am amazed that she seems so little affected by this experience and that the effects on her subsequent life are the reverse of what my attempts at psychological interpretation would lead me to expect:

When I was younger, when I lived in Preston, for some unknown reason my mother put me in Mount Street. It was a private orphanage [pause]. She was brought up there for quite a number of years and she put me in there. Still don't know why. And I was there about five and a half years. And you're brought up by nuns and your parents were not allowed to come and see you. And I believe I went home for a holiday and I wouldn't come back. So, that was part of my younger life, which was not a...me mother never explained why I was put in there.

Later in the interview, having heard stories of her involvement in church work, I return to this early experience and voice my curiosity that her early life should not have made her antagonistic towards the church. Barbara's explanation suggests a normalisation of her experience in the light of her own family history, culture and personality:

Well, you see, my mother, she was brought up in that convent for a number of years. So was her sister. Her dad...her own mother died when she were 28 so their dad was left with three children. One at two [years old]. I don't know how old Rachel was...and there was Rachel and me mother so he'd no choice but to put them in there. It was a private orphanage and she was in there for quite a long time. And then she came out and she had some relations in Preston, she lived wi them. Then, of course, she met me

³⁴ See Gubrium & Holstein 2009 p 37 on the ‘situational terrain of narrative reality’ and the importance of documenting and demonstrating the details and effects of co-constructing interview accounts.

dad. But she was always one of these for church. You mustn't miss church and it's such a saint's day today, don't forget that. When you went to school it was that all the time and you must go to church and...I've come 'ome from dancing about four o'clock in the morning, she's got me up at six to go to eight o'clock mass, seven o'clock mass, and I've only been in bed a few hours [...] She was very, very strict on going to church and that. Same as Whitsuntide, the processions they had, the boys had to walk, not me, no, no didn't matter about me the boys had to walk in the processions. The boys had to go in the choir and they'd a marvellous choir at Preston and the boys had to be in the choir and our life was all like that. It's a wonder it didn't put me off isn't it?

-But it didn't?

No, I'm just one of these, I'll help anybody. Doesn't matter what religion they are, who they are, what colour they are, doesn't matter, I'll help anybody. I've helped quite a few people. I've helped quite a few relations who've fallen out with their mother. I've said, 'Well, come and live wi me.' I've had a few. Yeh [pause] I'm just one of them, mine's an open door. If you can get in, come in, you know. It doesn't make any difference.

Barbara's working life began, like Henry's and James', at age fourteen and has extended into the present time. She started work in a bank, then moved to a cotton mill, followed by a period working as a nanny, then a job in the shoe trade and, when married and raising her two children, owning and running a variety of shops before taking up the work of housekeeper and custodian of the nearby church. At the time of interview she worked part-time in a charity shop.

Late in the interview, immediately following the extract above, Barbara also discloses that she has fostered seven children. She is now, in the midst of treatment for bladder cancer, active in providing domestic help for her adult children and in baby sitting for her tiny grandchildren.

Just done me son's washing. He likes it here because it comes out ironed, you see. That's his bag of stuff. He'll be [...] picking it up and bringing me some more. Then, me daughter's just gone back to work first time after havin't babies so her washin'll be comin [chuckle].

Although declaring herself to feel tired, Barbara gives the impression of being a person of tremendous energy and optimistic outlook. She even looks much younger than her eighty-one years and she talks self-deprecatingly and humorously about the way people comment on her wrinkle-free appearance.

8.3.2 Resilience and comorbidity

Frank (2008) suggests that one of the analytic questions which may be posed when considering narrative interviews is: 'What other stories is the person caught up in?' I began this study with an interest in cancer and comorbidity in older people and planned an interview series which would carry this twin focus. Over a period of time cancer moved to the foreground of my thinking and comorbidity took on a background character. I expected to hear about comorbidity (Kleinman, 1988 p.47) in the open-style interviews that I would conduct, but I decided not, specifically, to seek information about concurrent illness. This expectation was realised and 'comorbidity' (a technical medical term which, it is a safe bet, would be unknown to the participants) can be seen as providing one set of stories in which the person is caught up, to a greater or lesser degree, alongside the cancer stories. For some participants, their experience of, and management of, concurrent illness provides evidence of the resilient attitudes and behaviour which, I argue, characterise their response to cancer. For others, concurrent illness seems to be something that is simply in the background of their lives.

Previous and concurrent illness (comorbidity) appeared in many participants' lives. Jack 'lost count' of the number of operations he had undergone since retirement. Reggie, a more precise counter, itemised eighteen operations over the course of his life and gave a detailed account of two of them (perforated duodenal ulcer and subarachnoid haemorrhage). He had also survived throat cancer immediately prior to being diagnosed with lung cancer. Maria eventually retired from work owing to circulatory problems in her legs. Anne's early life was severely affected by rheumatic fever, which limited her mobility and her ability to learn:

When I was a teenager I couldn't walk very far without getting out of breath and that, so I never had much of a life, you know, as a teenager,

well, not till I had that operation [...] 1953 the operation was. So, what would that be, I'd be 24, 23 or 24 when I'd the operation and the doctor who'd been attending me, you know, he, [it was] mostly at night I got very out of breath, and he came out at night, the doctor. He was very good. [...] He had been over in London at a big hospital, was it Guy's Hospital, or something in London, and they were experimenting in heart operations then so he said I was a good one to send to them. And when I went that day [...] he told me he could do something for me. It was great, lovely. So, I'll never forget that, so [...] He took me in for tests and then, as I say, I went to the Royal and had the operation. And whenever I come home it was great. The first thing I done was went away across the fields for a walk, you know. It was great, so it was. Before that, like, I couldn't walk or anything, you know, so it was great, right enough [...] I didn't go to high school. I only went to ordinary school and then I did join the tech, to learn book keeping. But I couldn't keep it up so I just had to do what I had.

As if that wasn't enough to contend with Anne suffered a stroke while pregnant with her second child:

It affected me all down my right side, so. I was always right handed and now I have to do everything with my left hand. That was in Blackpool Royal in Blackpool. So, anyway, the doctor then, consultant, told me I'd have to have another operation on my heart which I had because he said it was a clot or something [...] my brain, you know. So, I'd another operation in Blackpool so that...I was fine then up till 1993. I had to go in for another heart operation and they put me in a mechanical valve, so that was in 1993.

Anne still lives with the effects of this stroke and my marginal note in the transcript of the interview reads: 'still has a dense rt. hemiplegia, which I assumed was from a recent stroke when I first met her. I was shocked to hear this.' The effects of the stroke did not impede her ability to bring up her children or to work for a living, though. She operated the telephone service for her husband's taxi service throughout their working life together.

In a long catalogue of previous illness stories, including at least two different cancers, Jean reveals an inner toughness in which she minimises all her troubles ('it's nothing isn't radiotherapy'; 'I've had loads of biopsies, they're not painful') and maximises her ability to endure ('you think you'll get me down, but you won't'; 'I felt I had to put up with it' (domestic violence)). Her attitude to cancer is fearless and she encourages people she meets to be fearless too:

I never, if I get a lump or anything like that, I never think 'Oh, I've got cancer,' you know, I've got cancer again. I never do. And people come in here, [husband] will bring them in, mainly men I must admit, they'll come in, and I know what they're coming for, and then they'll get round and they'll say, 'I've got cancer, how do you cope?' I say, 'Well, you walk on here [coastal path at foot of garden] and you can't go round that bend till you get to it,' I says, 'so just meet it when you get to it, you know. It's there, and you just put yourself in the surgeon's hands or the doctor's hands or whatever they decide to give you. I know it's not a single person's decision. You have your oncologist and your pathologist and there's a few and they make the decision which is best for you. And you won't regret going to [hospital]. There's nothing to be frightened of at all.'

Comorbidity loomed large in Jean's illness stories. Her inclusion in the study was based on her having lung cancer and at the time of the interview she was taking part in a clinical trial of the drug Tarceva, an epidermal growth factor inhibitor used to treat non-small cell lung cancer and under trial for the treatment of numerous other recurrent or metastatic cancers. But her illness stories also include a recent stroke and the ongoing effects of a fractured hip for which she feels she did not receive appropriate discharge care and follow-up:

I looked up and there were two ambulancemen at bottom o't'bed and, er, I said 'What's to do?' They said, 'You're goin' home.' I said, 'Well, I'm not supposed to sit in a wheelchair.' They said, 'Sister says you can sit in this wheelchair'. Well, apparently you're *not* supposed to sit in a wheel chair. You're supposed to sit at 90 degrees angle or lay down and, er, well, I thought, 'Anything to get out of here.' So, they put me in a wheelchair and they wheeled me out to t'ambulance. But when they got me in t'ambulance they did put me on't stretcher and I came home on a stretcher and they left me there [indicates middle of sitting room floor] Saturday lunchtime,

no care package, nothing. So. I'm two and a half years on and I still can't get any physiotherapy. I've rung all over and I've been all over and I still can't get any physiotherapy-cos I've no care package. [cough]. Me doctor's referred twice and he said 'I don't know what's going on. Ring x.' Rung x. 'Ring y'. Well I've rung y. 'Ring erm z up'. Well I've rung z up.

This story is one of many in which Jean portrays health professionals and health services, except doctors, in a poor light. She typically places herself at the controlling centre of her experience and when her management of other individuals and of systems does not bring the desired consequences she expresses dissatisfaction and criticism. Paradoxically, she also reveals a capacity for silent endurance, for putting up with things, which she attributes to her life experience of having worked long hours in a munitions factory during the war³⁵, combined with her childhood farm work and subsequent lack of choice about post-war transfer to work in the textile industry.

For Daniel, comorbidity was an asset. He modelled his reaction to cancer on his systematic self-management of his diabetes over the preceding twenty years:

You conform to what is required of you in terms of being sensible and what you eat and whatever you do. And that has, to a certain extent, if not to a large extent, has given me an advantage in dealing with other things such as cancer, in [that] you discipline yourself. You become used to this sort of procedure mainly because you have so many tablets to take. I'm on tablets for diabetes and you've to time that with food you eat etc etc. And I've found, over the period of time, that if I have a regular programme, daily programme, sounds a bit boring but you repeat that day in day out [cough] and the more you stick to it the more successful you are.

And I've found this out and it isn't easy always to adhere to because all sorts of events can crop up where it would tend to disrupt your timing, you know, and you've to try and work round it. But you have to be conscious of the fact that's what you're doing. But if you let things slip you suffer the consequences, so that's what I found out. I'm referring to diabetes

³⁵ Memory may be questioned here. During the war years Jean was aged 10-16 so it may be assumed that she could only have worked in munitions for a short period of time.

LIVING WITH CANCER IN OLD AGE:
A QUALITATIVE SYSTEMATIC REVIEW AND A NARRATIVE INQUIRY

because I've found that probably, as I've said, that's my best source of disciplining myself.

Overall, comorbidity stories were fewer in number and revealed effects less intrusive on daily life than I had anticipated in conducting interviews about illness with a study population of older people. Barbara's concurrent bladder cancer came as a surprise to her, and she was suffering side-effects of chemotherapy, but her life seemed not to be unduly disrupted by it. Pamela's asthma seemingly had the worst effects among those with concurrent illness. She had recently installed various aids to movement around the house and she terminated the interview because of breathlessness. Alec claimed his knee (damaged from playing football when he was younger, and awaiting surgery) gave him more trouble than his (advanced) lung cancer. Daniel's diabetes, as already seen, was under control and provided a model system for his management of cancer. Maria was taking medication for something which remained unspecified even on direct questioning. Richard was on tablets for high blood pressure. Don suffered from heart disease and had recently developed diabetes, which, he said, he had 'got well under control.'

8.3.3 Resilience in the context of relationships

Some participants were caught up in other stories too; notably, stories of family life³⁶. Frank (2008) supplements the analytic question: 'What other stories are people caught up in?' with the question, 'What differences depend on being caught up in those stories?' For Maria, being caught up in the story of her grandson's chaotic life seems to have a paradoxical effect in the difference it makes to her own life. On the one hand she attributes the start of her cancer to her anxiety about him ('Oh, gosh, I'm not surprised, I've got all worked up over him', see Chapter 5, p.124). On the other hand, her active concern for his welfare (he was in prison at the time of the interview) despite his repeated challenges to her generosity (the rest of the family have disowned him) is of a piece with her lifelong other-centredness and seems to displace, most of the time, any anxiety she feels about her own well-being. This concern for others

³⁶ See Moloney (1995 p106) on 'Finding Strength.'

rather than the self is another expression of hope, hardiness and resilience (Felten, 2000; Pentz, 2005).

In less dramatic fashion than in Maria's life other participants were also involved with, supported by, and still giving support to their families (see Emslie et al 2009 on mutual spousal support). Daniel's sons-in-law helped him with heavy gardening. Henry enjoyed his grandchildren visiting and lifting his spirits; and his two daughters helped with cleaning and shopping despite living in distant towns. Alec's three children, too, were active in helping with daily household tasks. Bernard and his wife, childless themselves, were active honorary grandparents to their GP's children. Michael took an active interest in the lives of his grandchildren and Reggie was more active than most in contributing to the welfare of younger generations in his family. Our initial arrangement for interview had to be postponed because he was 'on standby' to provide transport for other family members to visit his recently born great-grandson in hospital following urgent surgery. The interdependence at work in these relationships can be seen as another foundation on which resilience rested (Pentz, 2005).

8.4 Searching for contrary cases

I was sensitized to the concept of resilience as a fundamental feature in the lives of older people with cancer by the findings from my qualitative systematic review (Hughes et al 2009) and I found abundant examples of resilience in the interview transcripts, as shown in this chapter. Reflection on my underlying attitudes to the study and to the life stories told by participants suggested the need to interrogate this interpretation, which privileges resilience as the dominant, characteristic response of these older people to living with cancer (and in their life generally). The following extract from my research journal, August 12th 2009, illuminates this process of questioning and reveals an initial outcome which reinforces, rather than undermines, the dominance of resilience:

'Maybe I want to find [that resilience in old age is common] because as I anticipate getting older (and as cancer stories make their way into my life) I want to know that there are hopeful stories-of courage, of fortitude, of recovery-which can be my stories too. So, I need to look in the interview data for counter-stories, narratives which show or suggest the inability to

bounce back from adversity. But I can't think of any! How am I going to search? Or should I just listen again to all the interviews (as I began today) with this search in mind? Today, I noticed the reverse: a resilience story I had missed. Bernard is telling me about a perforated peptic ulcer, the result of taking NSAIDs for rheumatoid arthritis, for which he was hospitalised but which had begun to heal before finally diagnosed: 'So I was lucky, I escaped an operation. I nearly had an exploratory one but, fortunately, I didn't.

-That must have been painful though

Well, it was. But, you know, these things happen in life. You've got to cope with them (rising intonation and emphasis). Life has got to go on.'

It appears that 'Life has got to go on' could almost be an epigraph for the whole study. A doctoral study of thirteen older adults with cancer in the USA, discovered at a late stage of my research, confirms the dominance of resilience as a characteristic of older people's response to living with cancer (Pentz, 2005, 2000). Pentz (2005) draws attention to the origins of resilience research in studies of childhood and adolescence and notes that some authors have argued that young people have the 'reserve capacity' necessary for resilience to a much greater degree than older people. Since reserve capacity is 'equated with the ability to grow beyond current or normal levels of functioning' (Pentz, 2005 p16) it may be that 'resilience' is not quite the right word, or construct, to describe the quality of stoical endurance displayed by older people in this study. On the other hand, the strength of optimism and determination, accompanied by a present or future orientation, revealed in some of the narratives supports an interpretation of participants' attitudes as resilient.

8.5 Self and society: 'grand narratives' and the 'lens of culture'

A supplementary analytic question to Frank's (2008) 'What other stories are people caught up in?', which might help situate private individual experience in a broader social context, is to ask, "Are there points in all this storytelling where the personal life stories 'bump up against the century' (Crown, 2009), where the stories in which people are caught up may be part of a 'grand narrative'?" (Davey & Seale, 2002). Another way to think of this is to approach

the interviews viewed analytically through a 'lens of culture' (McCormack, 2004). Rather oddly, it seems easier to show which grand narratives do NOT drive the life stories of these individuals, the cultural phenomena which do NOT seem to be features of their experience. There are at least three.

8.5.1 The self-help movement

First, in relation to the concept of 'survivorship' there has grown a self-help movement, supported in the UK by cancer charities such as Macmillan Cancer Support and others. The first manifestations of this in the 1980s took the form of Cancer Support Groups, typically organized and supported locally by small charities or parts of the health service³⁷. Groups were run by volunteers, typically comprising people who had experience of a particular type of cancer. This type of mutual support has extended to the Internet where there now can be found a host of websites representing a 'community of survivors,' (www.oncologychannel.com accessed Aug 5th 2009) who communicate and share their experience electronically with people they probably have not met. These are sites for the exchange of information, advice, mutual support and emotional release.³⁸

Participants in the present study 'bump up against the century' by NOT being involved in this culture of organized mutual support and self-disclosure. Their level of self-disclosure seems to be influenced by their personality and habits, rather than by the gendered expectations of male stoicism or female expressiveness (Hilton et al, 2009): Jack is 'not gifted with words,' in his wife's report and, sure enough, he is a taciturn interviewee. Henry is loquacious, and the stories disclosed to a stranger (Kitwood, 1980) on a first meeting are full of rich detail. John affirms the opportunity to talk about his illness and the effects of treatment with fellow sufferers at the radiotherapy centre; Bill, as we have seen in Chapter 8, bemoans his experience that (at the same centre) 'nobody talks about your illness, do they?' Jean has a reputation at the oncology

³⁷ I contributed to the work of such a group myself, in Bradford in the late 1980s, in my role as a District Nurse. See Bradburn (2003 p.30) for details of more recent manifestations of such groups.

³⁸ See www.oncologychannel.com pages 'Living with...Share your story.' And their advert for National Cancer Survivors Day June 7 2009)

outpatient clinic for talking at length to anybody who will listen about her illness experience. Henry, as noted above, derives deep psychological comfort from what might be called the 'enabling self-talk' of his friend's positive thinking (Bloch, 1993). Their support comes from family, friends, neighbours, rather than from self-help groups.

8.5.2 The turn to complementary therapy for cancer

A second grand narrative which participants in this study do not seem to be part of is the turn to complementary therapy for cancer. As shown in Chapter 8, 'negotiating a plurality of therapeutic options' (Broom, 2009) is not a dominant feature of the treatment experience for most participants, even where the choice lies among conventional treatments. Complementary and alternative therapies are not referred to at all by participants in this study³⁹. This may be contrasted with findings of an American study a decade or so ago which reported that one third of 699 people aged 64 and over (average age of 72), and with the same cancers as participants in *Cancer Stories*, used complementary therapies in the early stages of cancer treatment (Wyatt et al 1999).

What reasons might be suggested to explain why participants in *Cancer Stories* do not speak of using complementary therapy? I think it is because people in this cohort do not partake of the 'increased individualization in contemporary cultural practices' which Broom (2009 p1051) notes in relation to complementary and alternative medicine (CAM) but which is also a feature of wider society. Their cultural practices, including assumptions and behaviours clearly shown in the data collected for this study, are rooted in family and community, in work and obligation, rather than in individual experience, choice and aspiration.

8.5.3 End of life care

Research shows that cancer patients often do not die in their place of choice (DOH, 2005 p.4) and it is still claimed (DOH, 2008) that death is not spoken of in

³⁹ Among respondents to the NAO Cancer Patient Survey (DOH 2005, p 29) usage of complementary therapies was still the exception rather than the rule and the proportion of patients using them declined sharply with age.

society, that it is taboo. Current health policy in England seeks to draw attention to the end of life in new ways (DOH, 2008) and to ensure that as many citizens as possible have a dignified death over which they have some control. Death was hardly ever mentioned by participants in this study. It was felt in the background for Alec, Bill and Daniel (all suffering from incurable lung cancer) and Alec had lost his wife to cancer in the fairly recent past. Reggie talked about death almost as something in the distant future, making sure he had all practical arrangements in place. In fact, as we have seen, he died within months of the interview. Don spoke about death at the end of the interview only to make a joke about self-termination should he develop Alzheimer's Disease. Richard hoped that treatment would 'buy him a few more years,' while Margaret simply reflected phlegmatically that 'everything comes to an end.' None of the other participants referred to death or, importantly, gave any signals that they were concerned with thoughts of death. They seemed firmly to situate themselves in life.

8.6 Summary

In this chapter I have drawn on the wider life stories told by participants, going beyond the specific illness narratives of the 'cancer stories,' to interpret their experiences of cancer in the context of their overall biography. I have argued that their reaction to cancer is marked by resilience and that this resilience derives from their life experience. They situate themselves as people with a future orientation, firmly anchored to an existential and ontological position which insists on endurance and is encapsulated in the colloquialism 'life must go on.' Specifically, resilience is shown in relation to participants' reactions to adverse life events (Bonanno, 2004; Bonanno et al 2002), to their experiences of comorbid illness and in the context of their family and other relationships (Hughes et al 2009; Polk, 1997).

Analysing the narrative data through the 'lens of culture' (McCormack, 2004) and in the light of 'grand narratives' (Davey & Seale, 2002) reveals that contributors to this study typically do not participate in significant, health-related, contemporary cultural phenomena. Unlike younger people with cancer, they exclude themselves from formalised types of group and interpersonal support,

whether face-to-face or internet-based, and they do not make use of complementary therapies. Neither, with one exception, do they seem to share the beliefs of health professionals and policy makers that it is a good idea to talk about, and to plan for, their own deaths.

Overall, the findings of this narrative study offer a positive picture of resilient older people, embedded in mutually supportive family and social networks, being offered a high quality of treatment and care in a well organised health system. Nevertheless, there is still excess cancer mortality in the over 75s in the UK, compared with the USA, for example, so broadening of cancer awareness, early detection and appropriate treatment remain important targets, along with the creation of new models of support for people living with cancer beyond treatment (DOH, 2007). In addition, according to some of the stories told by these participants, there is still a need to educate and support clinicians to provide the highest standards of psycho-social care. In the next, and final, chapter, I conclude the thesis with a review of some methodological and theoretical considerations and I suggest what significance may be drawn from the findings of my two studies.

CHAPTER 9

DISCUSSION

9.1 Introduction

The study of living with cancer in old age reported in this thesis is directed at answering the question, ‘What are older people’s subjective experiences of living with cancer?’ The study is comprised of two different investigations: a literature-based study taking the form of a qualitative systematic review (*Experiencing Cancer*, reported in Chapters 1 and 2), and an empirical study using narrative methods of inquiry (*Cancer Stories*, reported in Chapters 3-8). In this concluding chapter I summarise the key findings across both studies and consider their significance for our understanding of older people’s experiences of living with cancer. I discuss the challenges of comparing findings from two studies which attempt to answer the same question but which use different approaches. I review and reflect on the identification of a research problem, the formulation of a research question and the principal approaches adopted by way of investigation. I consider the strengths and limitations of the chosen research methods. I conclude the chapter, and the thesis, with some observations on the transferability of the findings to wider populations.

9.2 Summary and comparison of key findings from both studies

In this section I summarise the findings from both studies and consider the ways in which findings from the narrative study (*Cancer Stories*) can be seen to confirm, extend or contradict findings from the qualitative systematic review (*Experiencing Cancer*). The findings from *Experiencing Cancer* suggested that, across a heterogeneous population of 214 older people, aged 51-90, with a wide range of cancers at different stages, and living in four different countries, the experience of living with cancer was marked by ambiguity. Close analysis and interpretation of a secondary dataset derived from 11 reports of primary research revealed five domains in which older people’s experiences of cancer

could be categorised: i) the experience of bodily suffering, ii) experiences related to treatment, iii) the condition of empowerment, iv) states of mind and feeling and v) impact of having cancer on a network of relationships.

The concept of ambiguity emerged in the analytic and interpretive process because in each domain a continuum of experiences was indicated such that for many experiences reported there was a counter-experience. For example, bodily suffering was extreme for some people, depending partly on the type and stage of their cancer, whereas for others it was less marked. But even where suffering was intense, older people found a variety of ways to mitigate their suffering and to endure their experience of pain. Where emotional pain arose in response to the fear of death people were able to find consolations in religious belief or in their family and community relationships. Some people sought actively to empower themselves in exercising as much control as possible over their experience whereas others chose a more passive role; for example, in making decisions about treatment.

The central connecting motif of ambiguity was explored more intensively by investigating the data to discover 'dimensions of contrast' (Elofsson & Ohlén, 2004) and by the application of Bury's (1982) concept of 'biographical disruption.' Interpretation of the systematic review data in the light of detailed analysis using these methods confirmed a conclusion that, for the cohort of older people represented in these studies, experience of cancer was marked by a condition of ambiguity.

Data generated by narrative interviewing in *Cancer Stories* revealed experiences of a more homogenous population of older people, twenty men and women aged 74-87, with one of four common cancers, all resident in the same geographical region of north-west England and all treated at the same Cancer Centre. I analysed these data narratively, using the concept of the 'illness trajectory' (Corbin & Strauss, 1988) as a structural framework, along with methods derived from other sociological and narrative concepts (the 'grand narrative' and the 'lens of culture') which were designed to interpret the participants' private experience in a social context.

The ‘illness trajectory’ represents a temporal arc structured by central events or processes including recognition of the first signs of illness, the decision to seek medical advice, having investigations and receiving a diagnosis, undergoing treatment and continuing to live with cancer beyond treatment. Participants’ reported experiences under each of these headings were described and interpreted in Chapters 5-8.

The onset of cancer was experienced, perceived and acted on differently among the twenty men and women interviewed in *Cancer Stories*. Only one cancer was detected by pre-symptomatic screening. All the others presented with symptoms, some of which were ignored for months (breast cancer) and some of which could not be ignored (colorectal cancer). Delays to diagnosis arose from two sources: first, where participants held back from visiting the doctor because they were afraid to be told they might have cancer and, secondly, as a result of the inherent complexities of diagnosing cancer accurately. Among those participants who told a story of receiving the diagnosis there were varied reactions, ranging from shock to stoicism, and varied experience of being told in a sensitive way that they had cancer. With a few relatively minor exceptions participants reported satisfaction, sometimes in glowing terms, with their treatment, both in terms of their overall experience of interactions with health service personnel and with the surgical or medical procedures employed in the attempt to cure their cancer or palliate their symptoms. Even where there were permanent side-effects of treatment (for example, urinary incontinence following radical prostatectomy and radiotherapy) which were experienced as burdensome, participants responded with tolerance and forbearance, rather than dissatisfaction and complaint.

Analysis of life-story data in the interviews suggested that participants’ stoical, sometimes fatalistic, attitudes to having cancer were consistent with life experiences in which many of them had endured a range of hardships or major responsibilities in their personal or working lives. It is this experience of endurance, evident in the findings of *Experiencing Cancer* and found as a dominant theme in *Cancer Stories* in the form of resilience, which most obviously connects the two studies reported in this thesis.

There are challenges in ascertaining ways in which the findings from *Cancer Stories* can be said to confirm, extend or contradict the findings from *Experiencing Cancer*. Although focused on the same topic, the two studies employed different methods in studying slightly different populations. Box 9.1, p. 217) shows extracts from my field notes which indicate the continuing struggle I experienced in trying to make direct comparisons between the two.

I think there are some broad similarities and also some differences. Both studies reveal the importance of relationships in older people's lives. And they both show that older people with cancer are sometimes active in giving support to others as well as receiving it. Both studies show that, in general, older people prefer to delegate decision-making regarding treatment for cancer to their doctors. There are differences of emphasis here across the two studies: in *Experiencing Cancer* there is a strand of more definite partnership between patients and health care providers and in *Cancer Stories* there are examples of a more consultative or collaborative style of decision-making. In *Experiencing Cancer* there is some evidence of perceived age-related discrimination in access to treatment. This is completely absent in *Cancer Stories*.

There is more evidence of suffering, both physical and existential, in *Experiencing Cancer*. This is probably owing to the greater heterogeneity of the study population, which included more people who were closer to death. This is not to say that participants in *Cancer Stories* did not report experiences of suffering. For some, the shock of the cancer diagnosis caused intense suffering and some participants experienced great pain as a result of treatment. But reported or expressed suffering did not represent a dominant and overt theme of the narratives in the same way as it appeared in the secondary data set of the systematic review, despite the closeness to death of some of the participants in *Cancer Stories* (three of the five people with lung cancer died within months of interview).

There are differences of emphasis, too, in relation to the overarching themes in both studies. There is less evidence of ambiguity and of biographical disruption in *Cancer Stories*, where there appears to be a more uniform set of experiences across the cohort and where biographical continuity can be seen more clearly

than biographical disruption. But the core finding from *Cancer Stories*, that older individuals with cancer are resilient, **does** confirm and extend a finding from *Experiencing Cancer*. This can be seen in the concluding observations from each study:

Experiencing Cancer

The findings from this review reveal the multidimensional nature of older people's experiences of living with cancer, throwing into sharp relief both the sources of suffering endured and the resourcefulness and resilience (Nygren et al., 2007) older people bring to managing a changed life

Cancer Stories

I have argued that their reaction to cancer is marked by resilience and that this resilience derives from their life experience. They situate themselves as people with a future orientation, firmly anchored to an existential and ontological position which insists on endurance and is encapsulated in the colloquialism 'life must go on.' Specifically, resilience is shown in relation to participants' reactions to adverse life events (Bonanno, 2004; Bonanno et al 2002), to their experiences of comorbid illness and in the context of their family and other relationships (Hughes et al 2009; Polk, 1997).

It is interesting to speculate about alternative methods of analysis which might reveal similarities and differences between the two studies in more detail. I think there are at least two ways in which they could be synthesised to achieve this. One way would be to incorporate the findings from *Cancer Stories* into the dataset for *Experiencing Cancer*, using Sandelowski & Barroso's (2006) definition of a finding (quoted in Chapter 1, p.27). This is an intriguing possibility, but it would be a large-scale undertaking, partly because of the volume of material (the findings chapters from *Cancer Stories* extend to 100 pages) and partly because the incorporation of additional data would be likely to change the nature of the dataset such that a different approach to analysis may become necessary.

Another way to link the two studies analytically would be to analyse the narrative data using the five topics, or domains, identified in the systematic review data, along with the concepts of ambiguity and biographical disruption.

This might also be interesting and, probably, would be more easily achievable than the first alternative approach. The reason I chose not to do this in my analysis was that it seemed too mechanistic to take a set of themes which grew from the analysis and interpretation of one dataset and simply apply them to a dataset generated by different methods. In both of my studies the approach to analysis and interpretation emerged from close familiarity with, and hard thinking about, the particular data generated for each study. In both cases a genuinely organic, emergent process drove the analytic method. In the case of *Cancer Stories* this led to a narrative method of analysis which precluded using the themes from *Experiencing Cancer* as a coding frame.

In summary, then, resilience is the central concept which connects the two studies. It is the interpretive core which defines the experience of living with cancer in old age among participants in studies across Canada, Israel, Sweden, the USA and, now, the United Kingdom. This finding is also consistent with conclusions drawn from a doctoral study conducted in the USA, using in-depth interviews with thirteen men and women with cancer, aged 65 and older (Pentz, 2002). Pentz observes that, 'older adults are often viewed as frail and not able to contribute to society or continue to grow as a person. In contrast, the older adults in this study were mostly resilient and full of life, despite the possible devastation of cancer' (2002, p. v). This observation could hardly echo my own conclusions more closely.

9.3 Implications for practice

How does it help staff nurses working in a cancer ward, or social workers, community nurses, general medical practitioners (GPs) and others supporting people at home, to know that the people in their care, though very old and possibly with advanced cancer, are resilient? It should not mean that they can be left to look after themselves! But, knowing that many older people are resilient does mean that it is not to be assumed that they will simply succumb to cancer and die. It means that they should have access to the best possible treatment and services available, on an equal basis with other, younger, people with cancer. And it means that health and social care providers should be ready to help older people with cancer to expect and to plan for a life beyond

treatment. Nurses, social workers, and others should advocate for older people just as they would for people in other age groups. And, since the experience of having cancer is integrated into a whole life, it is probably helpful if professional carers can get to know the person they are caring for as well as they can. Biographical approaches to care (Clarke, 2000; Clarke et al., 2003., Kitwood & Bredin, 1992) can be helpful here.

At a policy level, the Cancer Reform Strategy (DoH, 2007) proposed a range of initiatives intended to strengthen and improve cancer services across the whole population (in England). The ages at which people are to be invited for regular screening for breast and colorectal cancer, for example, have been extended, though those over 75 will still not be targeted for regular screening. Indeed, none of the proposed initiatives focus specifically on the needs of people in the 'fourth age'. This is not necessarily damaging; on the one hand it can be seen as inclusive, not to make stereotypical assumptions of need. On the other hand, there is a risk of *exclusion* if particular population needs are not identified. It is to be hoped that work arising from the National Awareness and Early Diagnosis Initiative (NAEDI) (DoH, 2007) will show new directions for encouraging older people to seek help as soon as they become aware of symptoms. Similarly, the work streams of the National Cancer Survivorship Initiative (NCSI) may produce new ways of supporting older people living with cancer beyond treatment.

With the exception of some disclosure of cancer diagnosis which, in the report of participants, fell below the baseline for high quality practice, the treatment and care given to participants in *Cancer Stories* appear to have been exemplary. There was no indication that participants had been excluded from treatment on the grounds of age, compared with some reports in the findings from *Experiencing Cancer*. Continuing care seemed to be satisfactory for most participants, with the exception of one participant's dissatisfaction with arrangements at discharge from hospital. The extension of communication skills training for cancer care professionals proposed in the Cancer Reform Strategy may improve practice in diagnosis disclosure but, overall, the practice of cancer care in a north-western Cancer Centre, as revealed in the narratives of the *Cancer Stories* participants, could be a model for others.

9.4 Reflections on choosing a research question and designing a study

The research question underpinning both the studies reported in this thesis is a simple one: ‘What are the reported experiences of older people of living with cancer?’ Most standard research methods textbooks, in the world of healthcare at least, emphasise the importance of the research question in driving choices about the design and conduct of a study (Gerrish & Lacey, 2010; Parahoo, 2006). The research question itself should derive from a research problem. The research problem, in this case, is the perceived obscurity from the view of health professionals, researchers, policy makers and scientists, of older people’s subjective experiences of having cancer. This is a problem because, in the contemporary world of healthcare, therapeutic benefit is seen to follow from the public disclosure of inner worlds of sickness. To remain hidden is to be disenfranchised in some way. This invisibility seems to increase with advancing age. Consequently, the research focus chosen for this project was on the experience of men and women aged 75 and older.

My approach to this particular research problem and research question was to ascertain the current state of knowledge by searching for existing research literature, before designing a qualitative study to address any demonstrable gap in knowledge. As explained in Chapter 1, most of the scientific literature relating to older people and cancer is concerned with matters of epidemiology and clinical treatment. Older people’s subjectivity, their own accounts of their felt experience, is largely missing from the literature.

In the interpretive paradigm which influenced my approach to this research problem, research design is rarely fixed in advance but emerges over time and may undergo several iterations (Lincoln and Guba, 1985; Robson, 2002 and see Chapter 3). Consequently, my initial plan to conduct a conventional narrative or critical literature review was transformed into a decision to maximise the yield from the few studies retrieved which reported older people’s experiences of cancer by subjecting them to qualitative systematic review (Chapters 1 & 2 and see section 9.4.1). Eleven studies were reviewed, from four countries (Canada, Israel, Sweden, USA) with 222 participants aged 55-99. Because only two studies concentrated on a population of people aged 75 and older, and because none

were UK studies, I designed an empirical enquiry to investigate a more homogenous population, of people aged 75 and older, living in the North West of England (Chapters 3 & 4 and see section 9.4.2).

9.4.1 Qualitative systematic review: strengths and limitations

Qualitative systematic review is a relatively new approach to bringing together diverse studies to form a larger dataset which can be analysed and interpreted to produce new findings. It originates in the ‘meta-ethnography’ of Noblit and Hare (1988) which typically synthesised the findings of a small number of studies using similar methods. More recent work (Britten et al, 2002) has shown the approach to be effective in producing new knowledge from studies using different methods, though all located within a qualitative paradigm, and with larger numbers of studies (Paterson et al, 2001; Sandelowski & Barroso, 2003a).

I think there are two particular strengths of the method used in *Experiencing Cancer in Old Age*, influenced by the work of Sandelowski and colleagues (2006, 2003a, 2003b, 2002, 1997). First, the systematic and rigorous approach to defining what can be counted as the ‘findings’, which form the data for synthesis or, in Sandelowski’s term, ‘integration,’ of the studies under review. This approach produces a larger and much more detailed dataset than might be anticipated from a reading of a qualitative research report which might, typically, display a set of findings as a small number of themes. Because Sandelowski’s definition of a finding (see chapter 1 p.27) includes all the statements made by authors which derive from their data, close reading of a research report often reveals considerably more findings than the headline themes (414 findings from 11 studies in *Experiencing Cancer*) which expands the dataset for integrative analysis and, correspondingly, increases the scope for producing new interpretations.

Secondly, the method of introducing ‘imported concepts’ (see chapter 2 p. 61) as analytical tools enhances the possibilities for interrogating the secondary dataset and for producing interpretively rich conclusions. In *Experiencing Cancer* the concept of ‘biographical disruption’ originally produced by Bury’s (1982)

work with younger people in the early stages of rheumatoid arthritis, and applied since then in a number of health-related contexts, was usefully transferred to the context of older people living with cancer (chapter 2). The central finding of the systematic review, that cancer in old age is characterised by ambiguity, was confirmed by interpretation of the secondary dataset in the light of the six features of biographical disruption articulated by Bury (Chapter 2, pp.62-65).

Some limitations have been identified in this approach. In qualitative research, credibility derives to some extent from researchers paying attention, in their analyses and interpretations, to the real-world contexts in which their research data are generated. The ability to do this is compromised to a degree in secondary data analysis, in which access to the original contexts of production is necessarily denied. Sandelowski & Barroso (2006) acknowledge that the findings produced in a meta-synthesis or research integration study are third order constructs, composed at two removes from the utterances of research informants. To some authors, this presents a formidable obstacle to the credibility and utility of qualitative systematic reviews (Campbell et al 2003).

Overall, I think the methods used in *Experiencing Cancer* enabled a synthesis to be made which was rooted in a careful and comprehensive identification of a body of research findings. These data were then analysed and interpreted systematically to produce new insights into the experiences of older people living with cancer. The study has been published in a highly regarded peer-reviewed journal (Hughes et al 2009, included at Appendix 5, p. 260) and I have received appreciative commentary from colleagues seeking advice on conducting their own qualitative systematic reviews. I have also, on the basis of this work, been invited to write for a special issue of the International Journal of Older People Nursing.

9.4.2 Narrative methods: strengths and limitations

Narrative methods in social research seem to have arisen partly from a 'biographical turn' (Roberts, 2002) influenced by the Chicago school of sociology which produced rich accounts of individual lives, interpreted in the light of

social and historical context (Liebow, 1967; Plummer, 1983; Whyte, 1955).

Narrative is now a rich and diverse collection of research practices employed across a wide range of disciplines, put at the service of understanding complex social interactions and the meanings that individuals ascribe to their experiences and relationships.

Narrative methods of data generation focus on the collection of individuals' accounts of experience, told as stories. Events which took place over a period of time are recounted with varying amounts of detail and commentary from the teller regarding geographical or spatial location, characters and relationships, and links between one event and another (plot). Narrators may or may not position themselves consciously in the role of storyteller but in every case what they say may be considered a performance of some kind, the construction of which is influenced by social interaction, by the presence of an audience, an individual or a group of listeners (Brody, 2003 p38), in what Gubrium & Holstein (2009, p10) call 'the environment of storytelling'.

A possible limitation of the approach taken in *Cancer Stories* may be that the generation of data based, more or less, exclusively on formal interviews does not adequately represent the complexity of 'narrative reality' (Gubrium & Holstein, 2009). Gubrium & Holstein argue that the incorporation of ethnographic fieldwork, and the use of narrative data arising in naturalistic settings, can do much to enhance the understanding of stories as lived in society. The point is well taken, but, in regard to the narrative study reported in this thesis, Gubrium & Holstein's approach to analysing narrative reality was encountered too late in the process to affect the research design or methods.

Narrative methods of analysis may focus on the features of storytelling outlined above (the content of the story); on the shape, structure and linguistic pattern of the narrative (the form of the story); or on a combination of the two (Elliott, 2005; Lieblich et al, 1998; Riessman, 2008). What Gubrium & Holstein (2009) call the 'situated shaping of the account' (p 17) or the 'storytelling process' (p21) can also form useful foci of analysis, going beyond the narrower confines of the internal organization of a story. Analysis in *Cancer Stories* concentrates predominantly on the content of the narratives (Chapters 5-7) though,

periodically, the 'situated shaping of the account' and features of 'the storytelling process' are brought into view. In Chapter 8 the analytical range is extended to interrogate the data in the light of contemporary social contexts.

One of the strengths of narrative methods can be, at the same time, a limitation. The giving away of power and control in the interview which comes with the invitation to 'tell me what happened' means that interviewees may be more likely to follow their own course, to talk about what is meaningful to them, rather than feel constrained to answer researchers' questions. This is a strength when the hope is to generate a rich seam of storytelling. The limitation that comes along with this is the danger that the interviewee's discourse becomes dominated, or at least unbalanced, by stories and commentary which are not pertinent to the research questions. In the BNIM method (Wengraf, 2008) used in *Cancer Stories* this danger is avoided by careful construction of the interview setting, with a particular focus on the opening question (see Chapter 4) and then by trusting the process whereby meandering stories tend to come back on track, and along the way may present material which would never have been uncovered by more direct questioning.

Further limitations which pose potential threats, in particular to interpretive credibility, include some 'seductions' of narrative (Bruner, 1991; Riessman, 2010). 'Narrative seduction' occurs when a story is so crafted as to seem capable of only one interpretation (Bruner, 1991 p.9). In the research context, one form of this seduction is the tacit assumption that a single narrative interview represents a whole life story. In truth, it is clear that a single interview can only represent a partial life story but, the longer you work with the transcript, because you don't have anything else, it begins to look and feel like the whole (of a person's life) story. The effect of this is to leave a question mark over any interpretation that is made which uses data that purport to be 'life story' because they are necessarily partial and selective. There may be contradictory stories which are not told.

There is also what might be called an 'epistemological seduction' of narrative. I mean by this the assumption that knowledge can be derived from stories. I think this is a genuine threat to credibility when stories which are generated to be

representative of a predetermined class of narrative are offered as sources of knowledge; for example, stories produced by news media or charities which present cancer patients as heroic fighters to be celebrated as sources of inspiration. As I argued in Chapter 4, illness and life narratives generated for the purpose of research must be subjected to analysis and interpretation, not just celebration (Atkinson, 1997; Thorne, 2009). The threat is ever present, though. For example, in my representation of participants in *Cancer Stories* as resilient it may be that my interpretation was influenced by my inner celebration of what I heard and saw in their life stories, by what I saw as hope for my own future. Reflexivity, and renewed attention to the evidence in the interview transcripts, were my principal guards against this tendency.

Another seduction in narrative research is the tacit belief that it is bad news which makes an interesting or important story. Researchers' ears prick up during interviews, and their analytic eyes open wide reading transcripts, when people talk about the dramatic portions of their life story (child deaths-accident, murder, suicide; 'wife beating'). But, actually, these are not presented as defining moments; and, taken overall, the story told by respondents in *Cancer Stories* is a positive one, *contra* cultural representations of the miseries and vulnerability of old age.

Notwithstanding these potential limitations, I would argue that the particular strength of the narrative methods used in *Cancer Stories* lies in the open form of biographical data generation, which permitted an analytic view of participants' cancer experiences in the context of their life experiences. This enabled both rich description of their encounters with symptoms, diagnosis, treatment and survivorship and the identification of resilience as a core interpretive concept.

9.5 Concluding Observations

It should be noted that in the interpretive paradigm on which these studies are based, all findings and conclusions must be seen as provisional. These qualitative data are susceptible of multiple interpretations which are influenced by analysts/interpreters' prior experiences and perceptions, research orientations and cultural antecedents. The findings and interpretations presented here were

generated by me, in particular contexts. They are idiographic (pertaining to the unique individual) rather than nomothetic (capable of expression as a universal law). These findings and interpretations, then, are not necessarily transferable to cohorts of older people other than those studied. Nevertheless, I would argue that they offer new and useful insights into older people's experiences of living with cancer. As a version of reality they offer, in Bruner's term, 'verisimilitude,' rather than logical or scientific verifiability (Bruner, 1991, p.4).

The combined findings of *Experiencing Cancer* and *Cancer Stories* suggest that cancer presents, at the least, a disruptive potential in the life story of older adults, a disruption which is characterised by threats to bodily integrity, challenges to everyday living, spoiled hopes and fear of death. At the same time, partly because cancer is often only the latest in a series of adverse life events, inner resources of fortitude and hopefulness combine with family, professional and social support (Wallace, 2001) to produce a form of resilience which represents continuity in the life narrative and which mitigates the worst effects of disruption, even at an advanced stage of illness and among the oldest-old. The key contribution of the two studies reported in this thesis is to offer a counter-narrative to the societal expectation, or construction (Powell & Biggs, 2000), of vulnerability in old age; a counter-narrative in which the resources which older people themselves can bring to managing the life changes associated with advancing age and serious illness are brought into view and shown to be substantial.

Box 9.1 Extracts from Reflective Research Journal considering the challenge of linking two different studies

Dec 22nd 2008

Need to say something about links between systematic review and narrative study. I don't know yet what substantive links will be but already noting, during interviews and beginning analysis, comparisons with key findings from review. Eg narrative study population presenting a picture of less suffering than review population, though similar resilience in response to hardships encountered in the past (including deaths of adult children by murder and by suicide, divorce, deaths of spouses)... Reasons for this may include factors that contribute to confident self-disclosure such as the age and gender of the interviewer; younger and female may engender greater self-disclosure than older and male; or it may be that participants in the narrative study are receiving effective treatment and therefore experience fewer troubling bodily symptoms which in turn relieves the mental distress of living with a life-threatening illness.

Feb 5th 2009

How do emerging findings from the narrative study link to the findings from the systematic review? Tentatively, I can say in relation to this that in the narrative study: There is **less existential suffering**. For most, physical and emotional suffering is faced with fortitude and without anxiety. There is less bodily suffering too for most. Reactions to treatment have varied from terrible to minor. Persistent side-effects of treatment appear only in one person (John's incontinence following radical prostatectomy and radiotherapy).

The importance of **relationships** is the same: with **health professionals** (almost universal approval: occasional disrespectful nurses cited (Bill, Henry) and one deviant case (Pamela) disliked a consultant. Jean is a special case in that her interview is peppered with accounts of relationships with healthcare professionals, most positive but many negative (especially with nurses) and all designed to show her in a position of power); with **family members**, many of whom are living close by and are actively involved in a caring and supportive role; **with friends**, eg Bill still socialising regularly with work mates after 10 yrs retirement; Henry gained the greatest support from his friend's written mantras.

Resilience is the same but **ambiguity** is less. They are fatalistic and tough. 'It's happened. Get on with it.'

For most, there is less focus on **the body** and its restrictions and more focus on what capability for independent action remains. Some deviant cases where restricted activity and changed roles loom larger eg Bill, James, Pamela.

Treatment is accepted fatalistically ie 'the doctor says I need this so I will have it' and as though there is no other choice. There is no hint of any wish to decline treatment. Sometimes the offer of treatment is accepted enthusiastically (Henry) or gratefully. There is no indication at all in the narrative study, compared with the systematic review, of age discrimination in the availability of treatment.

Empowerment struggling to know how to compare with this one. I would say that none give a sense of having been disempowered either by their disease or its treatment or their relationships with health care professionals or indeed even by traumatic life events (1 lost a daughter to murder and suffered physical violence from husband; 1 lost a son to suicide; 1 lost 2 children, to cancer and to accident; at least 4 bereaved of spouses).

Mental and emotional effects. Most express gratitude for treatment combined with optimism, tinged with realism, for the future, or at least resignation to their situation. Though actually, for many, cancer now has a limited impact on their lives, even where it is advanced eg Don who is actively pursuing a creative business interest at age 84 and with the news that his prostate cancer is advanced. There is variation here though. John, an otherwise healthy and active 75 yr old, suffers severe incontinence as a side effect of surgery, made worse by radiotherapy. Only direct reference to sexuality is here. James suffers extreme fatigue from his ongoing chemotherapy and the effects of his gastric cancer. He was really the only participant to express any existential suffering in relation to his own disease, becoming emotional when talking about his grandchildren. Alec was emotional too, but in relation to losing his wife to cancer only a year before his own diagnosis. About his own illness experience he was more resigned. In daily life his orthopaedic problems (knees) have more impact.

April 1st 2009

I have a nagging feeling of things not quite having the 'fit' that I want them to have. There are at least two reasons for that, I think. One is that I feel apprehensive about being led down a route of making overt comparisons between my literature study and my narrative study, because they are different things. The literature study synthesises and interprets findings from 11 studies covering a heterogeneous population of people aged 55-90+, representing a wide range of cancers at different stages of progress and treatment, across four countries (Israel, Canada, Sweden, USA) and using a range of qualitative methods. The empirical inquiry studies a more homogenous population of older people aged 74-87, all resident in the same geographical region (NW England), with one of the four most common cancers (admittedly at different stages of progress

and treatment, but treated at the same cancer centre) using narrative methods. I feel that I would have to think very carefully about what I mean by 'comparison' to embark on such a venture, which has implications of measurement that I do not intend, nor am in a position to make.

March 8th 2010

I'm still resistant to trying to compare the SR and the narrative study but I do have to link them in some way. How am I going to do that?!.....they are linked by *resilience!*

Thesis word count: 72,686 words, including references but excluding appendices.

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Appendix 1

Research Protocol

Version 4

March 2007

Nic Hughes

Macmillan Research Fellow

Title

Cancer stories: the experiences of people aged 75 and older living in the North West of England

Background

Old age is defined variously in western countries. People aged 50 and above are described as being in the 'third age' and are the recipients of special services (education, insurance, holidays) provided for 'older people'. Withdrawal from mainstream working life at the official retiring ages of 60 for women and 65 for men is a further badge of old age. But increasing longevity, and better health, mean that for many individuals the sixth decade of life is not seen as a time in which 'traditional' experiences of old age (restricted life style and declining powers) are expected. Many individuals do not think of themselves as old at this time, except in terms strictly relative to chronology ie they are older than somebody who is 18 and older than the self they were at 18. In the seventh decade people may be more likely to think of themselves as old and by the eighth decade it is hard to avoid the full recognition of old age (Vincent 1999). The 'oldest old', individuals aged 80 and older, are increasing in number and are subject to periodic research investigations (Bury 1991) and press interest (The Guardian 2006; 2007).

Research Problem

Despite increasing longevity and generally improving health in the population the process of aging is associated with greater incidence of disease and illness, in particular of degenerative conditions such as musculo-skeletal disorders, ischaemic heart disease, neurological impairments and cancers. Co-morbidity is

common in individuals aged 70 and older (Stevenson et al 2004; Extermann 2000). Cancer has its highest incidence in older populations. There is an extensive literature reporting the incidence and prevalence of cancers in older age groups along with approaches to treatment and the effects and management of co-morbidity (Bennahum et al 1997, Extermann et al 1998, Satariano & Silliman 2003). However, the subjective perceptions of older individuals undergoing the experience of cancer remain largely unknown.

Aim of the research

The aim of this research study is to investigate the experiences of people aged 75 and older who receive a diagnosis of cancer. The research will reveal the views and opinions of older persons about the problems and challenges of living with cancer and, crucially, how health and social care professionals can best meet their specific needs.

In the framework outlined by Robson (2002)) the purpose of this research is predominantly *exploratory* rather than *descriptive or explanatory*. Important aspects of exploratory enquiry are that it seeks to find out what is happening, particularly in little understood situations; to seek new insights; to ask questions and to assess phenomena in a new light.

Overview of Research Design

This empirical study is one part of a doctoral study being undertaken by the chief investigator (CI) in the Institute for Health Research at Lancaster University. It is complemented by a systematic review and meta-synthesis of qualitative literature which reports cancer experiences of older people. The whole programme of study has received funding from the UK cancer charity Macmillan Cancer Support (formerly Macmillan Cancer Relief) under the terms of its Research Fellowship scheme, which provides reimbursement of salary for the principal investigator (0.5 for a period of 4 years) with some research expenses. The relevance and importance of the research have also been affirmed by members of four Consumer Research Panels, three of which are sub-groups of the National Cancer Research Institute (NCRI). Panel members have been consulted at early stages of the research design and their ideas have informed this protocol and an application for ethical approval. They have been invited to

contribute further commentary, as a 'virtual' advisory group, as the research progresses.

Since the principal focus of this enquiry is on participants' experiences a fieldwork design based on **biographical/narrative research** is appropriate, in which the research task is to collect, analyse and interpret individuals' accounts (stories) of their experiences (Roberts 2002; Cole & Knowles 2001).

Summary of Research Methods

- The primary method of generating data will be through in-depth interviews with a sample of men and women aged 75 and older. A research interview is a formal event which may not be every participant's preferred way of giving an account of their experience. Participants will be offered the opportunity to use other ways of telling their story if they so wish; for example, through a written account such as a journal or diary (**more detail pages 4-5, 11-12**).
- The study will be conducted within an ethical framework which seeks to maximise the wellbeing of participants who choose to contribute to the study (**more detail pages 8-11**).
- Audio-taped interview data will be transcribed to text for systematic analysis following the framework used by Riley and Hawe (2005). Journals or diaries will be analysed using the same methods. Transcripts will be returned to participants for verification of accuracy and additional commentary. Participants will also be invited to comment on the researcher's interpretations of the data (**more detail pages 12-13**).
- Findings from the study will be made available in summary form through a project website and in documentary form. Consideration will be given to dissemination through local meetings (**more detail pages 13-14**).

Research Questions

The fundamental purpose of this research is to gain knowledge of, and to understand, the impact of cancer on the lives of older people. What happens when an older person develops symptoms and signs of cancer? What is it like to receive a diagnosis of cancer and to go through what can be complicated treatments which older people often find it difficult to tolerate (Pergolizzi et al

2001). Having completed active treatment for cancer, what is the experience of everyday life 'living with' the after effects of the cancer. What if treatment is not indicated? What is the effect of all this on living with other chronic diseases or long-term conditions concurrently with the cancer? Answers to such questions have rarely been sought from older people themselves. Moreover, such older people are routinely excluded from clinical trials on grounds of age.

The provisional research questions in this study are:

- What is the impact of a cancer diagnosis on the person aged 75 and older?
- How are decisions about treatment made?
- What is the impact of cancer treatment on the life of the older person?
- What are older persons' reactions to being excluded from treatment?
- What is the impact of cancer on the person's daily life?

Sources of data

The primary method of data collection will be a series of in-depth interviews with up to 40 people aged 75 and older who have been diagnosed with one of the four most common cancers: breast, colorectal, lung, prostate. Interviews will have a dual focus: informants will be asked to describe their current experiences of cancer in the context of their experiences of ageing. Since reflection on ageing often involves review of earlier stages of life, an approach to interviewing which allows reflection on the whole life course is appropriate (Bornat, 2002). Interviews will be tape-recorded, with permission, and transcribed. Participants who prefer to contribute a written account of their experience, such as a journal or diary, in place of an interview will be invited to do so in a style and format of their choice. Guidance will be available from the Chief Investigator (see Data Collection below page 10).

All participants will be assured of confidentiality and all reporting of interview or journal data will be anonymous. All interview material and personal data will be stored securely, in a locked filing cabinet. Electronic data will be password-protected and stored on a portable hard-drive which can be detached from the computer for secure storage.

Findings from this empirical enquiry will be informed by a parallel study based on a systematic review and meta-synthesis of qualitative literature which reports older persons' experiences of cancer. Data for this literature-based study have been collected and preliminary analysis has begun (Feb 2007).

Study population and sample; study site and recruitment

Study population

The study population will comprise men and women aged 75 and older resident in the North West of England, who have been diagnosed with one of four common cancers: breast, colorectal, lung or prostate. The age group 75 years and over has been chosen because, although the population defined as aged 65-100+ is heterogeneous, the incidence of age-related physiological changes is reported to increase sharply between the ages of 70 and 75 (Gianni et al 2001). This means that a cut off of 75 years is likely to reflect more fully the complex intersections of cancer, comorbidity and old age (Thomé et al 2003) than a cut off of 65 years, the conventional beginning of 'old age' throughout most of the 20th century in western industrialised societies.

Study sample

Factors which influence decisions about sampling size in flexible designs/qualitative research include (Morse 2000; Robson 2002): *the nature of the topic* (fewer informants are needed if it is obvious and clear; conversely more informants are necessary if the topic is challenging and difficult to grasp); *the quality of the data* (fewer informants are needed if data are 'on target' and are 'rich and experiential'); *the study design and methods* (more data are acquired per participant with repeat interviews so fewer informants are needed; semi-structured interviews yield fewer data per person than in-depth interviews so more informants are needed). Morse (1994) recommends approximately 30-50 *interviews* (note, not informants) for ethnographic and grounded theory studies.

Taking account of the above recommendations, and placing them in the context of a biographical/narrative approach based on in-depth interviews which are likely to yield a lot of data, it is proposed to recruit up to 40 informants to the

study, ideally 10 from each of the four cancer groups targeted. Inclusion criteria will comprise:

- Men or women aged 75 or older
- Diagnosed with one of four targeted cancers: breast, colorectal, lung or prostate
- Be well enough to take part in at least one interview or otherwise provide relevant data (eg diary/journal). It is anticipated that interviews will be approximately 1-2 hours long.

Study site

It is proposed to base the study at the Royal Preston Hospital and to seek assistance with recruitment through the cancer multi-disciplinary teams. Consultant oncologists have voiced their support for the study and will be asked to identify eligible patients attending oncology clinics. The Lead Cancer Nurse has also agreed to support the study and will facilitate the Chief Investigator's attendance at clinics. The Lancashire and South Cumbria Cancer Research Network team is supportive of the study and has facilitated access to clinicians. The Research and Development Directorate at the Royal Preston Hospital is also supporting the study.

Recruitment procedure

Eligible patients will be informed about the project by clinical staff and invited to receive further information in person from the Chief Investigator who will be in attendance at oncology clinics. Potential recruits will be provided with written and verbal information about the study and invited to discuss their participation. Participants will also be invited to discuss their participation with family and/or friends before making a decision. A decision to participate will not be sought at the time of first contact with the CI but patients will have at least 48 hours in which to make such a decision. Opportunity will be given for further questions by telephone or email if wanted before deciding to participate.

Detailed verbal and written information will be given to potential participants by the CI about the purpose and methods of the study and what will be involved for participants. They will be informed that the study is not intended to provide

direct clinical benefit to participants but that it is hoped the findings will influence care for future patients. It is particularly important that it is made clear to participants that this study is not a clinical trial investigating the benefits of particular treatments.

Informed consent to participation in the study will be sought by the CI with the assurance given that participants may withdraw at any time without any impact on the health care they receive. The CI will seek training in methods of seeking informed consent. Confidentiality will be assured and participants will remain anonymous in all publications and disseminated material arising from the study. Participants will be assured that all personal and research data will be stored securely in locked filing cabinets and password protected electronic systems and that only *bona fide* personnel will have access to those data. *Bona fide* personnel include the CI, collaborating researchers and the research supervisor. Data will be recorded on a notebook computer that can be locked in a filing cabinet and will be backed up on a portable hard drive which can also be locked away.

Ethical considerations

Perceived benefits of the study

Cancer research has a high public profile in the United Kingdom, in particular through the activities of Cancer Research UK. Much of the research activity brought to the awareness of cancer patients and the public is concerned with the search for effective treatments. There is a powerful incentive for individuals suffering from cancer to take part in such studies. It is important that potential participants are helped to understand that taking part in the proposed study will not have a direct benefit on their health and will not affect any treatment for cancer which they may undergo. This will be achieved by providing written information, supplemented by discussion, in which the purposes and methods of the proposed study are expressed as clearly as possible.

Privacy/confidentiality

It is important in any research interview in which participants reveal their personal thoughts, feelings, ideas or experiences that participants are able to be

assured that their recorded statements are kept private and confidential. (Exceptions to this occur in oral history interviewing where it may be mutually agreed that interviews are made available to a wider audience). Participants in this study will be assured of confidentiality by the CI, who will conduct all interviews. This means that the CI, and collaborating researchers or clinicians who have access to data, will promise not to divulge participants' personal details, or the content of the interviews, to any third party not connected with the research study and will take steps to store securely all personal and interview data. Permission will be sought specifically from each participant to record the interview on digital audio recording media. Audio recordings will be transferred to computer at the earliest opportunity following the interview and will be password protected. They will be stored on a portable hard drive which will be kept in a locked filing cabinet, along with transcripts and other written data (journals, diaries or letters). Transcripts of interviews will be made anonymous, as will any statements made by participants during interviews which are reported in the research findings. Permission to quote from interviews, also made anonymous, will be sought specifically.

Anonymised written data (transcripts and copies of journals) will be retained for the maximum length of time permitted under the Data Protection Act. Audio recordings will be destroyed at the end of the study. Original written materials such as journals or diaries will be returned to participants.

Discomfort (physical) during interviews

Participants in this study will be older men and women who by virtue of their inclusion in the research are suffering from diseases, that is, the objective presence of pathology, of various kinds. The extent to which they will be suffering illness, that is the subjective experience of symptoms, at the time of recruitment to the study and participation in interviews is unpredictable. Measures to minimise any physical discomfort to participants during the process of the interview will include:

- Reassurance that participation is entirely voluntary and that the participant may withdraw if feeling unwell enough to participate, either before or during an interview . Should the participant wish to negotiate

participation at a subsequent date if feeling well enough this will be accommodated.

- Venues for the interview will be negotiated with each individual and it is anticipated will take place either in the participant's home or in the hospital outpatient clinic. If the interview is to be conducted in the hospital a room will be sought which is comfortable, with ease of access and where refreshments can be provided. Rooms will be sought which have loop induction systems for the assistance of participants whose hearing is impaired and who use a hearing aid.
- Participants who wish to contribute but anticipate that they may become overtired in an interview which might last up to 2 hours will be advised to make arrangements to ease their withdrawal if necessary eg bring a family member or friend who can take them home before the end of the interview. Stanworth (2004) found that her fears of overtiring participants were unfounded, citing one terminally ill 76 year old interviewee who was surprised to find that what he thought had been a pleasant twenty minute conversation had in fact lasted nearly 1 ½ hours.

Distress (emotional) during OR AFTER interviews

Talking about painful experiences can be therapeutic but it can also be distressing. It is important that people who are being asked to talk about their experiences are made aware that this reaction may occur. On the one hand, positive feelings may come from being listened to, and possibly seeing experience in a new light as a consequence; on the other hand, negative feelings of renewed pain may arise as distressing experiences are re-told and imaginatively re-lived. Participants in this study will be informed about these important matters in the information leaflet they will receive before agreeing to take part in the research.

Should the recollection of painful experience during the interview become distressing the interviewer will honour the person's experience by pausing the interview and giving the participant time to express their feelings if they so wish. If the participant is too upset to continue the interview then the interview will be terminated. Participants will be assisted to make the decision that best meets their own needs. Should this situation occur the researcher will use skills

gained from many years of nursing and of pastoral work in education to comfort the participant. If distress persists beyond termination of the interview participants will be referred to the cancer care team at the Royal Preston Hospital for further support. At all times the participant's needs will take priority over the demands of the research. It is worth noting that in Stanworth's study (2004) of spirituality at the end of life, using in-depth interviews with people who were in some cases within days of their death, the occurrence of emotional distress was rare.

Data collection

Data will be collected through a series of individual, face-to-face in-depth interviews and/or through a diary or journal. Interviews will take place in the participant's home unless the participant objects, in which case a suitable venue will be sought in the hospital or cancer centre at Preston. The reason for siting the interview at the participant's home is that in the type of narrative research proposed the dominant interest is in the life of the participant which is *other* than their life as a patient (Frank 2000). Hospital surroundings necessarily, if implicitly, focus all concerned on the life-as-patient. Participants may be accompanied at interviews if they wish.

A single interview lasting approximately 1-2 hrs will be the basis of an individual participant's contribution. The optimum length for a single interview in narrative research is around 90 minutes (Hermanowicz 2002; Seidmann 1995 cited in Elliott 2005). Participants will be informed in advance of the likely length of the interview. This is not only courteous but gives participants a sense of how much detail they might provide in the interview (Elliott 2005). If an interview needs to be curtailed owing to participants' tiredness a follow-up or continuation of the interview at another time may be negotiated.

Interview questions will be open, inviting participants to tell their story (Stanworth 2004). It is important in narrative research not to restrict or confine what people may say by asking too many questions (Elliott 2005). People who wish to take part in the study but who do not wish to be interviewed will be invited to submit a written journal of their experiences. Similarly, this will be an open request to write about their experiences in whatever style and form

they choose. Guidance will be given to those who may want to write but who feel the need to have a more prescribed structure. The Chief Investigator's experience in teaching reflective writing to health professionals and students will be of assistance here. Any data collected in this way will be stored securely, as described for interview data.

Data Analysis

Interview data will be audio-taped with participants' consent and transcribed to text for analysis using a published interpretive framework (Riley & Hawe 2005). Computer software (AtlasTi) will be used to manage the data and assist with analysis. Data from initial interviews will be subjected to a first-level analysis to inform subsequent data collection and to evaluate interview technique. Data from journals or diaries will be analysed in the same ways as interview transcripts.

Narrative research is an interdisciplinary venture and analytical frameworks can be found in a range of domains eg discourse analysis, socio-linguistics, literary criticism and poetics. The following features of a 'story', a participant's account of their experience, are among those which can be subject to analysis and interpretation:

- purpose/s of the storytelling: overt and hidden
- structure/s of story: overt and hidden
- 'outcome/s' of the story
- language: literal and symbolic
- social relations and power structures between key actors (implicit or explicit)
- 'positioning' of the narrator in the story
- narrator's positioning of others in the story
- narrator's sequencing of events
- positioning of the recorder (ie the interviewer)
- recorder's impressions, perceptions, judgements, interpretations
- placing of the whole story in a social and political context
- links to other research (including results of qualitative meta-synthesis conducted in parallel with this empirical inquiry)

Riley & Hawe (2005: 230) provide a useful interpretive framework which can provide a starting point for analysis. In Riley & Hawe's scheme analysis focuses on:

- Language: *are the sentences descriptive, consecutive, consequential, evaluative, transformative?*
- People: *who is mentioned in the telling of events, and who is absent, and what are their roles?*
- Context: *what is the nature of the storytelling occasion?*
- Content: *what is the 'plot' ie what are the stories about?*
- Form: *the flow of the narrative over time ('stable' 'regressive' 'progressive')*

Reporting and dissemination of findings

I think it is important that the findings from the study are disseminated as widely as possible. I propose an ambitious and extensive dissemination strategy. In addition to writing a PhD thesis, I will produce a number of interim reports for Macmillan Cancer Support, together with a final Report. I also expect to publish a number of papers in peer-reviewed journals and to disseminate findings at relevant professional and academic conferences. I will seek the collaboration of Macmillan Cancer Support in organising meetings to report the findings to people affected by cancer, including those who contributed to and participated in the research. A booklet, written in non-professional, non-technical language, which summarises the methods and findings of the project will be made available for those who cannot attend meetings. A project website will also display the findings and implications of the study. Finally, I plan to write a book based on this research.

Summary timetable

- Preparation (REC submission, arranging NHS R & D approval/honorary contract, collaboration at research site): Jan-June 2007
- Recruitment, data collection, analysis and interpretation: July 2007-Dec 2008
- Writing report: Jan-June 2009
- Feedback meetings: Sept-Dec 2009

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A QUALITATIVE SYSTEMATIC REVIEW AND A NARRATIVE INQUIRY

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Appendix 2

Cancer Stories: experiences of people aged 75 and older living in the North West of England

Participant Information Sheet

My name is Nic Hughes. I am a Lecturer in Nursing at the University of Leeds and a postgraduate research student at Lancaster University. I am inviting you to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and family if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Cancer is more common in older people, who also are more likely to have a range of other long-term diseases. But there is not much research which tells us what it is like for older people when they get cancer. This study looks at what older people experience when they get cancer. Participants will be asked to talk about their experiences, to tell their 'stories', of having cancer in one-to-one interviews with me or by writing down some of what happens to them and what they feel about it. A collection of these stories can then be used to help doctors, nurses and other carers to understand more fully what cancer is like for older people and to base the treatment and care they provide on the knowledge of what older people think, feel and say about their experiences. The study is part of my PhD research work at Lancaster University.

Why have I been chosen?

I am asking people over 75 who have a diagnosis of one of the four most common cancers; of the breast, colon, lung, or prostate; to take part in the study.

Do I have to take part?

No - taking part is voluntary. It is up to you to decide whether or not to take part. If you decide not to take part you do not have to give a reason, nobody will be upset and the standard of care you receive will not be affected in anyway. If you do decide to take part I will ask you to sign a consent form and give you a copy to keep. If you decide to take part, and then change your mind you are still free to withdraw at any time even after you have signed the consent form. You can contact me on the number below if you change your mind.

What will I be asked to do if I take part?

If you agree to take part, I will arrange an appointment with you for a discussion or “interview” about your experiences of having cancer. The interview is likely to last between 1-2 hours. If our discussion seems that it will last longer than 2 hours I may ask you if we could meet for a second interview. So at the least I will ask you to talk to me on one occasion for about 1 hour, at the most we might meet on 2 occasions but for a maximum of 2 hours each time. This will depend on how much you feel you have to talk about and is likely to be different for different people. You can agree to only one meeting if that is as much as you want to do. The interviews can be arranged to take place wherever is most convenient for you. I can visit you at home if you wish, or we can arrange to meet in the hospital or clinic if that suits you better. If you need to make a special journey for the research we can refund your travel expenses. With your permission these interviews will be audio-recorded, but you can request that the recording be stopped, replayed or edited at any time.

If you want to take part in the study but you are not keen on the idea of meeting a researcher to talk about your experiences you could tell your ‘story’ in writing. You could either keep a diary of what happens to you over a couple of months or just write a story of what you experience. If you think you might like to do this I will be able to talk to you about it in a bit more detail before you decide.

I may also wish to look at your medical records, with your permission, for background information on your health, illness and treatments.

What are the possible disadvantages or risks of taking part?

This study involves talking to me in an interview or writing down some of your experiences. There should be no risk to your physical health in taking part, but some people may find it upsetting talking or writing about their feelings and about coping with difficult circumstances. If you do begin to find talking about your experience upsetting we will stop the interview until you feel better, or stop it altogether if that is what you would prefer. If you find that talking about these things has upset you deeply I will offer to talk with you about what might help you to feel better.

What are the possible benefits in taking part?

The information you give will help us find out how doctors, nurses and other carers can best meet the needs of older people with cancer. In addition, some people say they have found it helpful to have the opportunity to talk about their experiences and feelings in studies similar to this. The study is not designed to provide any direct benefit to your condition or general health.

Will my taking part in this study be kept confidential?

Recordings of interviews will only be listened to by the principal researcher, Nic Hughes. They will be stored securely in a locked filing cabinet. You will be able to have a copy of the recording to keep if you would like one. All written information (for example, transcripts of interviews and other written material such as diaries which you provide for the study) will be made anonymous by removing material which might identify you. You will be able to read the transcript of your interview and make comments on it if you want to. Transcripts and other written materials will also be stored securely in a locked filing cabinet and will be destroyed or returned to you (for example, diaries or journals) at the end of the study.

I may use quotations from interviews in documents and publications about the study and these also will be made anonymous so that you cannot be identified. None of the information that you give in either interviews or written materials will be fed back to your doctor, nurses or any one else, unless you make criminal disclosures or suggest that you may harm yourself or others.

What if there is a problem?

If you have any questions or concerns about the research you can contact me, Nic Hughes, on (0113) 343 1289. If you have a complaint about the conduct of the research, you can contact Professor David Clark, PhD Supervisor at Lancaster University, on (01524) 592 513.

What will happen to the results of the research study?

The final results of this study will be known in 2010 when all interviews and documents have been obtained and analysed. I will let you know the results when they are available. I may ask you to check some of the early findings for me before then. Results will be reported in articles, books or meetings so that the best possible use can be made from the research, but you will not be identifiable in any way.

Who is funding the research?

This study is being funded by Macmillan Cancer Support, a long-established and well-known charity which supports people affected by cancer.

Who has reviewed the study?

The study has been approved by the Lancashire and South Cumbria Research Ethics Committee and by the Lancashire Teaching Hospitals NHS Foundation Trust's Research and Development Committee.

What happens now?

Thank you for considering taking part in this research. I will contact you in a few days when you can ask any questions you have and discuss whether you would like to take part. Or you can contact me by 'phone or email.

Nic Hughes

Macmillan Research Fellow/Nursing Lecturer, University of Leeds

Postgraduate Research Student, Lancaster University

Tel: Leeds 0113 343 1289

Tel: Lancaster 01524 592 513

Email: n.d.hughes@leeds.ac.uk

Appendix 3

The 'Cancer Stories' Research Study

- What?** A research study exploring the experiences of people aged 75 and older who are living with cancer
- Why?** To gain deeper insight into the needs of older people with cancer
- Who?** People aged 75 and older who have a primary diagnosis of **breast, colon, lung or prostate** cancer
- How?** Talking to a researcher (Nic Hughes) from Lancaster University about your experiences of living with cancer
- Where?** Wherever is most convenient for you. The most obvious choices are at your home or here at the hospital in a quiet and private room
- When?** At a time convenient to you.
- Contact?** Nic Hughes



☎ 0113 343 1289

✉ n.d.hughes@leeds.ac.uk



Appendix 4

Consent Form

Cancer Stories: Experiences of People Aged 75 and Older

Name of Researcher: Nic Hughes

Please initial box:

- 1 I confirm that I have read and understand the information sheet dated March 2008 for the above study.
- 2 I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected.
- 3 I understand that my responses will remain confidential unless I make criminal disclosures or indicate that I may harm myself or others.
- 4 I understand that comments I make may be reproduced in publications, but that my comments will be anonymous.
- 5 I give permission for the interview to be recorded.
- 6 I am willing to allow access to my health records by the researcher.

