Realising the potential: Developing qualitative longitudinal methods for understanding the experience of metastatic colorectal cancer

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EMMA K CARDUFF

Thesis presented for the Doctor of Philosophy

The University of Edinburgh

2013

DECLARATION

I hereby declare that

i.   This thesis has been composed by myself

ii.   The work presented within this thesis is my own unless otherwise stated

iii.   This work has not been submitted for any other degree or professional qualification

Emma Carduff

October 2012

ACKNOWLEDGEMENTS

I am grateful to the ESRC for funding this PhD studentship. Firstly I want to thank to my supervisors, Marilyn Kendall and Scott Murray for putting their faith in me, and for their guidance and support, both academically and pastorally. Thanks are also due to my colleagues in the Primary Palliative Care Research group for their ongoing support and encouragement. Particular thanks go to Debbie Cavers for sharing her experiences and offering advice and to Pam Warner for always encouraging me. I am grateful to Lesley Gardener for transcribing my interviews when I could do no more, and for always showing an interest. Many thanks go to the staff at the recruiting centre who assisted me in identifying the participants, in spite of being so busy and who always made me feel welcome.

Special thanks go to my fellow PhD student Anna Lloyd who has been with me every step of the way. I would also like to thank my family for always loving and supporting me. I am very grateful to my friends who have always encouraged me and have given me a healthy work/life balance. I am especially grateful to Anna for proofreading my thesis.

I want to offer a very special thank you to my husband James, who has put up with my fluctuating moods, offered valuable advice and beyond all else, has always believed in me. To James, and my beautiful son Hugo, who arrived during the course of this PhD, you have both inspired me to do my best and for that I will be forever grateful.

Finally I want to thank the participants in this study who gave up their time to share their very personal stories with me. This thesis is dedicated to those who are still enduring the disease, those have sadly lost their lives, and to their loved ones.

ABSTRACT

Background

Qualitative longitudinal research (QLR) has a long history in the social sciences, where its theoretical basis is well established. Qualitative longitudinal (QL) methods are gaining popularity in health care research for exploring the dynamic experience of illness. However, methodological development of QLR is limited within the health literature, and there are very few studies examining the experience of people with colorectal cancer (CRC). Moreover, such studies describe the experiences of those surviving CRC and the voices of those with advanced disease who are approaching the end of their lives remain largely unheard.

Aim and objective

This study explores the potential of QL interviewing to examine the experiences of those with advanced, metastatic, CRC. I investigate how QL interviews can be best utilised to explore the participants' accounts of their experiences. I specifically examine the added value and costs of a flexible approach with regard to the frequency and timing of longitudinal interviews. Analytical approaches to QL data are examined to determine their overall value.

Methods

Sixteen patients with metastatic CRC and eight of their family carers participated in narrative interviews at three time points over the course of a year. The study was designed to include two groups of participants. The first, a routine interval group where interviews were carried out at regular intervals of six months; the second, a flexible interval group where there was an interview at baseline followed by monthly phone calls to track changes in the participants' circumstances, with a view to conducting the interview as change was occurring. The data were analysed at each time point, and longitudinally using narrative and thematic techniques.

Findings

The QL design enabled a trusting relationship to evolve, such that private accounts of experience were disclosed. Thus, a nuanced and contextualised understanding of the experience of metastatic CRC materialised. Overall the accounts of CRC were characterised by uncertainty, yet at the same time death was a certainty. Over time, this dual narrative led to participants feeling themselves to be in an ambiguous and liminal state. Some participants described a loss of sense of self, yet others maintained their identity. The work that participants carried out to manage their sense of self changed, as they moved from a collective to an individual identity. In the flexible interval group, monthly telephone calls produced an even more profound research relationship and further enriched the accounts. However, early interviews were only conducted on two occasions and more ethical issues arose as a result of the increased contact.

Conclusions

By exploring the potential of QL methods, this study has developed the methodology for researching the experiences of those with serious illness. QL interviewing elicits a deep understanding of metastatic CRC that appreciates notions of temporality, process and change. Regular contact with participants between interviews can further enrich the accounts, and is a useful strategy for tracking changes given the unpredictable nature of advanced disease. This thesis showcases the cross-sectional and longitudinal opportunities that QL analysis presents; yet also highlights how longitudinal narrative analysis allows a story to unfold over time which reflects the beginning, the middle and for some the end of the illness experience. Although QL analysis is time consuming, and more contact can amplify ethical issues, the benefits outweigh the constraints.

ABBREVIATIONS

ASAP	As soon as possible
CAQDAS	Computer Analysis Qualitative Data Analysis Software
CHD	Coronary heart disease
COPD	Chronic Obstructive Pulmonary Disease
CT	Computer Tomography
DAFNE	Dose Adjustment For Normal Eating
ESRC	Economic and Social Research Council
CRUK	Cancer Research United Kingdom
GP	General Practitioner
HIV	Human Immunodeficiency Virus
ITU	Intensive care unit
IV	Intravenous
MDM	Multi-disciplinary meeting
MRSA	Methicillin Resistant Staphylococcus Aureus
NHS	National Health Service
OF	Organ failure
QL	Qualitative longitudinal
QLR	Qualitative longitudinal research
RA	Rheumatoid Arthritis
REC	Research Ethics Committee
TB	Tuberculosis
UK	United Kingdom
VCRM	Voice Centered Relational Method
WGH	Western General Hospital
WHO	World Health Organisation
WTCRF	Welcome Trust Clinical Research Facility

OVERVIEW OF THE THESIS

In chapter one I provide the rationale for this PhD study which explored the potential, and subsequently developed QL methods for understanding the experiences of those with CRC. I introduce the academic and clinical contexts in which the study took place and cite the aim and research questions.

In chapter two, the first of two literature reviews, I describe the experience of CRC. Within the chapter I situate CRC within the wider context of the illness experience using two theories, namely biographical disruption and narrative reconstruction. I conclude this chapter by highlighting the limitations of the current body of knowledge and thus argue the application of a QL design for exploring the experiences of those with advanced CRC.

In chapter three I examine the literature relating to QLR methods. I explore the definition of QLR and consider when the design should be used. I examine the methods and analysis that are currently used in QLR, and consider the practical and ethical challenges that are associated with it. I consider when and how QL methods are used in health care research. In so doing I demonstrate that there is a gap in the health care literature for the methodological exploration that this PhD study has undertaken.

In chapter four I detail how the study was conducted. I introduce the theoretical framework upon which my conduct, analysis and interpretations are based. I then recap the aims and objectives and describe the design of the study. I describe how the participants were recruited and how the data were generated and analysed. I also consider the importance of reflexivity in qualitative research and describe what I, as the researcher bring to this research.

In chapter five I describe the sample. Due to the complex chronology of this QL study I also present timelines of when the interviews and telephone calls were conducted with each participant. This also highlights the attrition that took place as participants died.

Chapter six represents the first of three chapters which illustrate the findings of this study. In chapter six I explore the data to report how the experiences of the group change across time - time being one of the three facets of QLR. In part I, the themes as they arose at each time point are described. In part II, I provide an overview of the findings and consider the broad threads which are woven through the cases and through the time points. I conclude by considering if the experience of CRC is a liminal one, where the person feels 'betwixt and between', and how the concept works as a framework for the data.

In chapter seven, I consider the data through time, at an individual level. In the first part, I describe six case histories, using diagrammatic timelines to highlight the themes which arose at each time point. In part II I consider the process of identity loss – process being the second facet of QLR. I reflect on the relevance of Bury's (1982) theory of biographical disruption for describing the participants' accounts of their experiences.

Chapter eight considers how change is best captured – change being the third facet of QLR. By comparing two case studies I explore the added benefit of the flexible approach to generating data, where monthly telephone calls were conducted to assess and explore change. I consider how the added context and the relationship that developed as a result of the increased contact, led to a more nuanced understanding of the participants' accounts. I also reflect on the ethical challenges which I encountered as a result of the flexible approach. I conclude this chapter by considering when the flexible approach is justified and thus move towards a more detailed discussion of the QL method.

In the concluding chapter (nine) I directly respond to the research questions which were introduced in chapter one. I highlight the overall potential of QL interviewing and how

this PhD study has developed the method for the future. I also discuss the limitations of the study. I end the chapter with the implications for future research and with my reflections on conducting the study.

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CHAPTER ONE
Introduction

1.1 In the beginning

This thesis marks the culmination of my journey as a PhD researcher. I set out to explore the potential of qualitative longitudinal (QL) methods to examine the experiences of those with advanced, metastatic colorectal cancer (CRC) who are approaching the end of life. In this chapter I provide the background and rationale for this PhD study, describe the clinical context in which the study was carried out and introduce the aim and research questions.

This studentship was funded by the Economic and Social Research Council (ESRC). An influential discussion paper which was commissioned by the ESRC in 2006, suggested that qualitative longitudinal research (QLR) can provide a new perspective on 'established areas of social inquiry', and recommended that QLR be used to study the illness process (Holland et al., 2006: 2). The topic area arose as a result of work carried out in the Department of General Practice (GP) at the University of Edinburgh, which considered the illness trajectories of those with serious illness, and the impact on them, their carers and relevant health professionals. These studies which adopted a QL approach raised questions about the potential of QL methods for describing the experiences of those at the end of life (Cavers et al., 2010; Kendall et al., 2006; Murray et al., 2005; Murray et al., 2004; Murray et al., 2002; Murray et al., 2007b; Murray et al., 2010; Pinnock et al., 2011; Sheikh et al., 2008; Sikasote et al., 2011; Worth et al., 2009; Murray & Sheikh, 2006). Therefore, this methods PhD is an extension of the work which has been already undertaken.

The ESRC has long had an interest in QLR which is evident as they funded the first major QL study in the United Kingdom (UK) entitled Timescapes (Timescapes: An

ESRC Qualitative Longitudinal Initiative, 2012). There is agreement that QLR is a good approach for examining change. QLR broadly includes follow-up studies, tracking studies and mixed methods studies with a QL arm to the design (Holland et al., 2006). However, the contemporary definition of QLR is that it is both planned and prospective. Although QLR has a long history in social science disciplines such as anthropology, criminology, education, psychology and social policy it remains underutilised in health care research (Murray et al., 2009).

This thesis reports my experience of conducting a QL study. I carried out narrative interviews, over the course of a year with 16 participants who had been diagnosed with terminal metastatic colorectal cancer and some of their carers. With a view to addressing the issue of *when* to conduct QL interviews, eight of the participants were interviewed at routine, six monthly intervals and eight were telephoned every month to encourage a flexible approach to interviewing. This study generated a wealth of data allowing me to describe the participants' experiences of illness, as well as to explore the potential and develop the method.

1.2 A note about language

It will already be evident that this thesis is written in the first person. Reflexivity is integral to good practice in qualitative research. As the researcher, 'I' am embedded in this story meaning my reflections are essential in this thesis. I examine the practice of reflexivity in more detail in chapter four. For the most part, I referred to those who took part in this study as participants, unless it was necessary to differentiate between patients and carers (for example when naming quotes). I wanted to ensure that those with cancer were not defined by their illness, and that those who were described as 'carers' were not merely seen as caregivers. In keeping with this, each participant was given a pseudonym, a decision which will be discussed in more detail in chapter four. For the purpose of this study, carers were defined as someone who was sharing the experience of illness with the person with CRC. Likewise, I have generally referred to those who

care for the participants in a professional capacity as health or social care professionals. Finally, this study adopted a narrative methodology and thus produced stories. Throughout the thesis I use narrative, story and account synonymously.

1.3 Clinical context

There have been several QL studies which explored aspects of the illness experience of those with CRC, but few have recruited people with advanced disease. To my knowledge there are no QL studies to focus exclusively on the experiences of those with metastatic CRC. Colorectal cancer is the third most common cancer suffered by people in Scotland, and there were 3351 new diagnoses in 2008 of which 63% were men and 37% women (Information Services Division, 2010). However, in Scotland CRC is still the second highest cause of death for men and the third for women (Information Services Division, 2010), although screening for bowel cancer has reportedly reduced the number of deaths by 27% (Libby et al., 2012). The cause of CRC is still largely unknown, but research has identified risk factors such as; a higher than average intake of red and processed meat; alcohol; smoking and a diagnosis of diabetes; obesity; ulcerative colitis or Chron's disease[1]. Genetic factors have also been linked to CRC and it is thought that those who have had a first degree relative with bowel cancer have an increased risk (Cancer Research UK, 2012).

As figure one (page 4) illustrates, there are a number of areas within the bowel where CRC tumours can present. The largest percentage of tumours are located in the rectum (27% of all cases of CRC) and the sigmoid colon (20% of all cases of CRC).

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[1] Ulcerative colitis and Chron's disease are inflammatory diseases of the bowel.
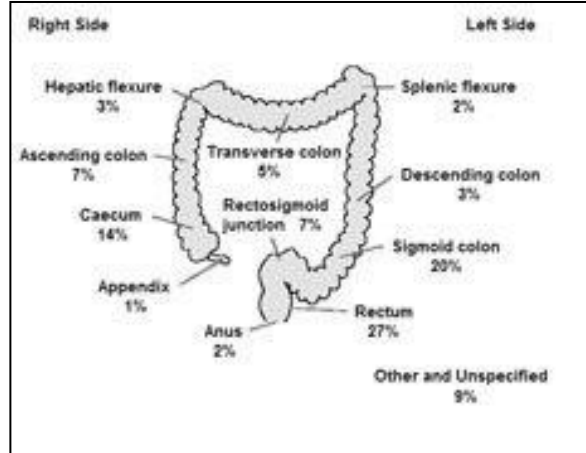
Figure 1. Diagram representing the percentage of CRC tumours at different locations of the bowel
Source: CRUK (2012), last accessed 14th September, 2012

Prior to recruiting the participants into this study I consulted with the doctors and specialist nurses at the recruiting centre about the management of CRC patients. The flowchart in figure two illustrates a typical pathway for someone with CRC. Those who present with CRC can be broadly categorised into two groups. The first is the sub-acute patient who usually presents to their GP with bowel symptoms such as bloating; bleeding; irregular bowel habits; abdominal pain. This patient may also present with tiredness; weight loss; anaemia and abdominal (often liver) pain. These latter signs are suggestive of metastatic disease. The acute patient often presents in distress to the emergency department as the tumour is obstructing the bowel, which can result in vomiting and extreme abdominal pain. This scenario is considered a surgical emergency and immediate action would be taken to resolve the problem. This patient may also present with distant metastases, but the priority in the early period is to resolve the obstructed bowel. Although the initial management of the two categories differs, the later management, treatment and out-patient follow-up is the same, as figure two (page 5) illustrates.

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┌─────────────────────────────┐          ┌─────────────────────────────┐
│   SUB-ACUTE PRESENTATION    │          │    ACUTE PRESENTATION       │
│  Patient presents to GP with │          │  Emergency admission with    │
│  signs and symptoms of bowel │          │  acute abdominal pain        │
│         disturbance          │          │  ±obstruction                │
└─────────────────────────────┘          └─────────────────────────────┘
              │                                          │
              ▼                                          ▼
┌─────────────────────────────┐          ┌─────────────────────────────┐
│  Sigmoidoscopy/colonoscopy   │          │  Imaging to determine the    │
│         and biopsy           │          │  presence and extent of      │
│                              │          │         tumour               │
└─────────────────────────────┘          └─────────────────────────────┘
              │                                          │
              ▼                                          ▼
┌─────────────────────────────┐          ┌─────────────────────────────┐
│  Imaging to stage the tumour │          │ Surgical intervention if     │
│  using Dukes' stages (CT,    │          │ required Dukes' staging      │
│       MRI, PET scan)         │          │       determined             │
└─────────────────────────────┘          └─────────────────────────────┘
              │                                          │
              ▼                                          │
┌─────────────────────────────┐                         │
│  Results of scans and        │                         │
│  biopsies are reviewed       │                         │
└─────────────────────────────┘                         │
              │                                          │
              ▼                                          │
┌─────────────────────────────┐                         │
│  Is pre-surgery radiotherapy │                         │
│  or chemotherapy required to │                         │
│     shrink the tumour?       │                         │
└─────────────────────────────┘                         │
              │                                          │
              ▼                                          │
┌─────────────────────────────┐                         │
│  Surgery – tumour in bowel   │                         │
│        is excised            │                         │
└─────────────────────────────┘                         │
              │                                          │
              ▼                                          ▼
        ┌─────────────────────────────┐
        │  Dukes' B, C and D - Referral │
        │  to oncology out-patient      │
        │          clinic               │
        └─────────────────────────────┘
                      │
                      ▼
        ┌─────────────────────────────┐
        │  Chemotherapy treatment       │
        │  within 8 weeks of surgery    │
        └─────────────────────────────┘
              │                 │
              ▼                 ▼
┌──────────────────────┐  ┌────────────────────────────┐
│ Adjuvant chemotherapy │  │ Palliative chemotherapy –  │
│  – aim is to cure     │  │ aim to relieve symptoms    │
└──────────────────────┘  └────────────────────────────┘
              │                 │
              ▼                 ▼
        ┌─────────────────────────────┐
        │  Regular follow-up with       │
        │  colorectal nurse specialists │
        │  and oncologists at           │
        │  out-patient clinic           │
        └─────────────────────────────┘
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Figure 2. Management pathway for a patient with CRC at the recruiting centre

CRC is categorised according to four Dukes' stages, A to D.

- Stage A is the least severe, meaning the tumour is contained within the bowel wall
- Stage B means that the tumour has evaded the wall of the bowel but is not present in the lymph nodes
- Stage C means that the cancer has spread to the lymph nodes
- Stage D means that the cancer is advanced and has metastasised the another part of the body (Cancer Research UK, 2012)

The likelihood of dying from CRC is increased if the sufferer presents with late stage disease (Cancer Research UK, 2012). The participants in this study have Dukes' stage D cancer which, in England between 1996 and 2002 accounted for 9.2% of all diagnoses of CRC (National Cancer Intelligence Network, 2012). For those with CRC, metastases usually present on the liver and the lungs. The five year survival rate for those with Dukes' stage D disease is 6.6% compared with 93% for those with Dukes' A (National Cancer Intelligence Network, 2012). Thus, specialist palliative care is recommended for those with advanced CRC who experience complex physical and emotional symptoms (Scottish Intercollegiate Guidelines Network, 2011).

1.3.1 The provision of palliative care

The World Health Organisation (WHO) suggests that palliative care is an essential aspect of cancer care and define it as,

> "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." (World Health Organisation, 2002)

Moreover WHO (2002) define the aims of palliative care as,

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death

- Integrates the psychological and spiritual aspects of patient care

- Offers a support system to help patients live as actively as possible until death

- Offers a support system to help the family cope during the patient's illness and in their own bereavement

- Uses a team approach to address the needs of patients and their families

- Will enhance quality of life (QoL), and may also positively influence the course of illness

- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy and radiotherapy, and includes those investigations needed to better understand and manage distressing clinical complications (World Health Organisation, 2002) http://www.who.int/cancer/palliative/definition/en/ last accessed 20th August 2012.

As this final objective suggests, the provision of palliative care should occur early in the illness trajectory, it is not just about improving the experiences of the last few months of life. Living and Dying Well: a national action plan for palliative and end of life care in Scotland was published in 2008 and was designed to ensure good palliative care for all across Scotland. In keeping with the WHO's (2002) objective to encourage early palliative care, the Living and Dying Well action plan highlights triggers to assess palliative care needs which includes the diagnosis of progressive or life-limiting illness (Scottish Executive, 2008).

1.4 Aim and research questions

This thesis reports the findings of a methods PhD which was funded within the Computing, Methods and Technology stream of the ESRC. However, it will become clear that through exploring, showcasing and developing QL interviewing and analysis, I have been able to describe accounts of the dynamic experience of CRC. Although this study did not set out

to describe the experience of CRC, understanding the accounts of the participants was a necessary and welcome outcome, as the literature review will highlight.

The overall aim of this study was to examine the potential of qualitative longitudinal (QL) interviewing for exploring the illness experience of patients with metastatic colorectal cancer and their carers.

Three research questions were posed to achieve this aim.

1. How can qualitative longitudinal interviews be best utilised to explore the illness experience?

2. What is the added value of a flexible approach with regard to the frequency and timing of longitudinal interviews?

3. Which approaches to analysis are most valuable for qualitative longitudinal interviews?

CHAPTER TWO
Experiencing colorectal cancer: A review of the literature

"Serious illness is a loss of the 'destination' and 'map' that had previously guided the ill person's life: ill people have to learn 'to think differently.' They learn by hearing themselves tell their stories, absorbing others' reactions, and experiencing their stories being shared" (Frank, 1995: 1)

2.1 Introduction

The aim of this chapter is to evaluate and synthesise empirical and theoretical literature which is relevant to the experience of advanced, metastatic CRC. In so doing I have constructed this chapter to reflect several broad areas of the literature; in the first section I will present the findings from an evaluation and synthesis of the general CRC literature. This section will also consider the experience of dying from advanced cancer and caring for someone with advanced cancer. In the second section I discuss the two theories which are commonly described in relation to the illness experience; namely biographical disruption and narrative reconstruction. I conclude this chapter by considering the limitations of the current body of knowledge.

2.2 Review methodology

Given the vast and diverse array of cancer and illness experience literature, I carried out a systematic search using a number of databases to find relevant qualitative and quantitative original research; review articles; discussion articles and editorials. The search encompassed biomedical and social science databases including OVID Medline, CINHAL, PsychInfo, ASSIA and Web of Knowledge. I was alerted to relevant articles on a weekly basis via email alerts from particular databases and, likewise, email alerts with the contents page of relevant journals were sent to me upon publication[2]. Greater

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[2] Journals included; Qualitative Health Research; Qualitative Inquiry, Journal of Health Psychology; Social Science and Medicine; British Medical Journal; Psycho-Oncology; Chronic Illness

emphasis was given to qualitative studies as they would offer more insight on the subjective experience of cancer. I conducted a fourfold search of the literature. Firstly, I searched for CRC specific studies but, given the relatively small number, I widened the search for potentially relevant articles about cancer more generally[3]. Overwhelmingly the cancer literature described the experience of survivors so I focused the search on the chronic illness literature and the end of life literature[4]. Further reading highlighted further literature so snowballing techniques were also used throughout the search. I also searched for particular authors who were seminal in the field and conducted cited reference searches for relevant papers, texts and authors.

Grey literature also informed this literature review. The experience of cancer is regularly portrayed on television, and in the media given the large number of people who suffer from it. Where possible I watched and read relevant pieces to gain perspective on the cultural portrayals and understandings of cancer. The review to follow encompasses the findings of my literature search and discusses the experience of CRC in terms of empirical and theoretical insights from past works. I will first evaluate and synthesise the literature relating the experience of CRC. I will follow this with a discussion on the theories of how we understand the experience of illness hereby situating CRC literature amid the sociology of illness.

2.3 Living with colorectal cancer

I identified a total of 34 studies to be included in this review. Despite the large numbers of people with CRC and the high mortality for those with advanced disease, only two

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[3] Search terms included; (Colorectal OR bowel) cancer AND experience; cancer AND experience; cancer AND transition; (patient* OR illness) AND experience AND cancer AND qualitative; cancer AND journey OR trajectory

[4] Search terms included;
illness AND experience; illness AND disruption; illness AND adaption; illness AND narrative; (Colorectal OR bowel) AND (death OR dying); (Colorectal OR bowel) AND metastasis; sociology AND (death or dying)

studies solely considered the experience of those with advanced, metastatic disease (Sjovall et al., 2011; Houldin & Lewis, 2006). Overwhelmingly the studies that were uncovered during the literature search for this review reflect the experience of those who are surviving CRC, rather than those who are dying from it. Having said this, six studies included those with advanced disease as they recruited participants to reflect the varying Duke's stages of disease (Browne et al., 2011; Rozmovits & Ziebland, 2004; Ramfelt et al., 2002; Little et al., 1998; Shaha & Cox, 2003; Sahay et al., 2000).

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2.3.1 Making sense of the diagnosis

Shock was a common response to being diagnosed with CRC et al., 2011; Houldin et al., 2006; Taylor, 2001). Participants had to make sense of their diagnosis after the initial shock of having cancer had been processed. Houldin and Lewis (2006) conducted a qualitative research study with 14 patients to describe the experience of living with advanced CRC. Overall, Houldin and Lewis (2006) found participants had to 'salvage their normal lives.' Their findings suggest that there are six categories involved in how patients make sense of their diagnosis; asking 'why me?'; worrying about the implications of the disease; coming to terms with the uncertainty; engaging in a life review; drawing on faith and confronting mortality (Houldin et al., 2006).

Participants' desire to find the reason for getting cancer through questioning 'why me?' was also reported by Dunn et al (2006) in their qualitative study about the dimensions of quality of life for those with CRC. The authors conducted in-depth interviews with 11 patients to explore their experiences of CRC and how they perceive their quality of life (Dunn et al., 2006). The researchers adopted a multi-method approach, insofar as two focus groups were conducted to further explore the themes which arose from the interviews, which improves the trustworthiness of the findings. Dunn et al (2006) reported that participants wanted to understand how they had got CRC hence asking 'why me?' particularly when they felt they had a healthy lifestyle. However Dunn

(2006) also found that older participants perceived cancer as an inevitable part of aging (Dunn et al., 2006).

The longitudinal aspect of this PhD study will enable me to explore how this changes over time. Do those who initially experience shock and question 'why me?' reach acceptance as they approach the end of their lives? I will return to this idea later in this chapter in relation to the impact of illness upon identity.

2.3.2 Loss of control

Feelings of loss of control were a common response to the diagnosis of cancer and seemed inherent to the process of making sense of the diagnosis (Houldin et al., 2006; Worster & Holmes, 2008; Shaha et al., 2003).

2.3.2.1 Bodily control

CRC commonly presents with rectal bleeding, altered bowel habits and, for some, abdominal pain (Broughton et al., 2004; Cancerbackup, 2007). The physical problems associated with CRC mean patients feel that they lose bodily control insofar as the bowel may be unable to function in the normal way (Desnoo & Faithfull, 2006; Houldin et al., 2006; McCaughan et al., 2011; Beech et al., 2011). Beech et al's (2011) QL study was designed to develop a grounded theory which could explain recovery from early stage CRC (Beech et al., 2011). Beech et al (2011) suggest that personal control is undermined by the patients' failing trust in their bodies and that over time the 12 participants in their study were able to restore a sense of wellness, where trust was regained through meaningful activities and listening to their bodies (Beech et al., 2011).

Furthermore, surgery remains the definitive treatment to remove the tumour, as indicated in the introductory chapter (page 4). Unfortunately, recovery from surgery can lead to many more problems such as; digestive problems, reduced bowel control, urgency, more frequent bowel movements, diarrhoea, constipation, increased flatulence and sexual

problems (Browne et al., 2011). Although some of these problems improved over the period of recovery in Browne et al's (2011) study, they also found that digestive problems, tiredness, and for one participant, sexual problems persisted (Browne et al., 2011).

2.3.2.1.1 Social isolation

McCaughan et al (2011) described that feeling a physical loss of control over bowel habits resulted in social isolation; a finding that is evident in a number of the papers I reviewed (McCaughan et al., 2011; Rozmovits et al., 2004). McCaughan et al (2011) reported the findings from the first wave of interviews in their QL study which explored and compared the experiences of 24 men and 23 women with CRC. The researchers conducted four interviews over 18 months with each participant; 1) after diagnosis and surgery; 2) after chemotherapy; 3) six months after chemotherapy and; 4) 12 months after chemotherapy.

According to the literature, loss of physical control is just one of the reasons for social isolation. Other reasons reflected psycho-social and spiritual issues and included changes in the patients' sense of self and how they viewed their relationships (Rozmovits et al., 2004; Taylor, 2001; Simpson & Whyte, 2006; McVey, Madill, & Fielding, 2001). Taylor (2001) qualitatively researched the experience of CRC patients just after their diagnosis. Taylor's (2001) study is strengthened by the fact that; firstly she sent the transcripts back to the participants after the interview to check the accuracy, and secondly, having identified the initial themes during her analysis she discussed these findings with three participants to ensure her initial interpretations represented what the participants thought. One of the main findings of Taylors's (2001) study was that participants felt 'on their own' after the diagnosis. Taylor (2001) described that following the diagnosis participants were 'removed from the here and now' (Taylor, 2001). Social isolation was more pronounced due to the embarrassment that participants felt about the disease. Indeed Taylor (2001) describes how one participant in her study felt that people were 'talking about his cancer' (Taylor, 2001). Taylor's (2001) findings

were supported by Little et al (1998), who likewise found that participants with CRC felt alienated and socially isolated after the diagnosis (Little et al., 1998).

2.3.2.2 Emotional control

Further loss of control is experienced in existential and psychological terms. For example Worster and Holmes (2008) noted that patients felt out of control if they adopted a passive stance with their health care providers by relinquishing decision making. This study was designed to describe the participants' experience after surgery for CRC. Worster and Holmes (2008) found that prior to surgery patients felt threatened by the decisions they had to make and were resigned to giving control to the health professionals looking after them (Worster et al., 2008). Although Worster and Holmes (2008) had aimed to study the post-operative experiences of participants receiving surgery, they ended up reporting the pre-operative experiences of patients. The reason for this was that the analysis of their interviews revealed that the participants had a need to narrate their diagnosis story. As Worster and Holmes (2008) planned to research the experiences of patients after surgery, not the pre-operative experiences or diagnosis, the findings have to be interpreted with care (Worster et al., 2008). Having said this, their findings are supported by Shaha and Cox (2003), who also found that patients relinquished control to health professionals after the diagnosis, in their QL study of seven patients with CRC (Shaha et al., 2003). Shaha and Cox (2008) found that participants in their study felt powerless to make decisions due to the threat of death upon them, and for this reason their sense of control was given to those caring for them. Moreover McVey (2001) suggests that going to hospital lowers control further (McVey et al., 2001).

More recently Sjovall et al (2011) reported that giving control to the health care system was associated with both positive and negative feelings. It could be seen as a positive in that it showed trust in the providers of health, but negative in that patients felt excluded from decision making processes which left them feeling vulnerable. Sjovall and colleagues (2011) conducted a multi-perspective study of 12 patients with advanced

CRC and nine of their partners. Although the transcripts were analysed as groups of patients and groups of partners, as opposed to patient dyads[5], the paper gives equal weight to the experience of the partners (Sjovall et al., 2011).

2.3.2.3 Finding meaning in illness

The literature suggests that in order to make sense of their illness patients attempt to find meaning. Sjovall et al (2011) reported that the patients in their study found psychological meaning in treatment. Treatment was perceived positively; it gave hope, security, a purpose, and meant that the patients felt that they were fighting the cancer rather than giving in to it. Consequently when no treatment was available patients felt abandoned, anxious, and frustrated (Sjovall et al., 2011). However, more often the search for meaning was reported in the context of spiritual/existential aspects of the illness experience. As Shaha and Cox (2003) reported, the diagnosis of cancer caused the patients in their study to question the meaning in their lives. The patients' previous beliefs were challenged by the presence of illness so that individuals had to find strategies to cope with such disruption (Shaha, Cox, Talman, & Kelly, 2008).

Likewise, the main theme found by Ramfelt et al (2002) was described in their paper entitled 'Attempting to find meaning in illness to achieve emotional coherence – The experiences of patients with CRC' (Ramfelt et al., 2002). In this study, 52 participants with CRC were interviewed on three occasions in order to explore the meaning of illness. At the first interview the authors used an interesting technique of inviting participants to choose one of eight categories which best described how they assigned meaning to their illness. The categories were namely; challenge, enemy, punishment, weakness, relief, strategy, loss and value. The interviews which followed explored the participants' chosen meaning. Although an interesting and fairly unique technique, the authors do not make clear whether or not participants were given the opportunity to re-evaluate the meaning of their illness at subsequent interviews. This presents a potential

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[5] Linked interviews where multiple perspectives are gained on a single phenomenon.

limitation of this study, particularly given the QL design, where the authors had the opportunity to explore change. Nevertheless, the authors found that participants attempted to find meaning in two dimensions. The first of these was that of 'unified embodiment' – a positive perspective that saw sub-themes including gratefulness, confidence in oneself and others, and looking forward to creating a new future. In this approach the self and body were united and in control. In opposition was the second dimension entitled 'dichotomised embodiment' which reflected the participants' struggle with their damaged body. The themes included altered self-value, loss of temporality, and infringement of body integrity. Issues of disembodiment were also evident in the literature and are of particular interest in CRC due to the loss of control that patients experience over physiological bodily processes.

The search for meaning can impact psychological and spiritual/existential wellbeing. In 2006, Lee and colleagues conducted a randomised control trial (RCT) to assess the impact of a meaning-making intervention for breast cancer (experimental group = 23 participants; control group = 29 participants) and CRC (experimental = 12 participants; control group = 10 participants) patients (Lee et al., 2006). The intervention comprised four individualised sessions with the researcher and the participant in addition to the usual package of care given by the hospital. Those in the control group received the usual care package only. The participants in the experimental group were asked to review their cancer experience in the context of other historical life events using a chronological timeline (much like a narrative, qualitative research interview). The patients then participated in three tasks which were designed to encourage reflection. In the first task the participants were asked to revisit events since their diagnosis. In the second they were asked to reflect on past life events and embed the cancer narrative within their biography. Finally, in the third task they were asked to acknowledge their own mortality. Although the numbers were small for a RCT and the CRC group were under-represented, the study reported statistically significant improvements in self-esteem, self-efficacy, and optimism in the intervention group when compared with the control group (Lee et al., 2006). This PhD study will explore how the search for

meaning changes over time and in what way it impacts psychosocial and spiritual wellbeing.

2.3.3 Uncertainty

Uncertainty was reported as a significant aspect of the CRC experience in a number of the papers I reviewed. According to Shaha and Cox (2003) uncertainty is felt in response to being faced with a life threatening disease and is multi-dimensional (Shaha et al., 2008). Beaver et al (2010) found that the participants in their study were uncertain about what to expect from the CRC and the surgery (Beaver et al., 2010). Fear of recurrence was cited as the main reason for uncertainty by Simpson and Whyte (2006) in their qualitative study of eight patients who had completed treatment for CRC (Simpson et al., 2006). Akin to Simpson and Whyte (2006), Taylor et al (2011) also reported that uncertainty about recurrence caused anxiety, in addition to reporting that patients who survived the cancer expressed uncertainty about how to move their lives forward (Taylor, Richardson, & Cowley, 2011). McCaughan et al (2012) also recognised uncertainty in relation to the fear of recurrence in the third and final interviews of their longitudinal study (McCaughan et al., 2012). Although Simpson and Whyte (2006), Taylor et al (2011) and McCaughan (2012) focused on the experience of survivors, their work highlights how uncertainty may always exist even after the physical illness has been cured. As Taylor et al (2011) report, the patients in their study could no longer take their health for granted as they had done prior to the diagnosis (Taylor et al., 2011).

According to Sjovall et al (2011) uncertainty for those with advanced disease was related to their thoughts about the future and their families, which is in contrast to concerns about physical deterioration. Uncertainty was also a key aspect of the experience for partners, and like the patients, it was related to the unknown trajectory of the future; the extent of the disease; how long their partners had left to live, but moreover they expressed uncertainty about how their partners with cancer really felt

(Sjovall et al., 2011). This latter point highlights the challenges people face in terms of communicating effectively with one another.

These papers support Browne et al's (2011) finding that uncertainty exists at every stage of the illness trajectory (Browne et al., 2011). Browne and colleagues (2011) found uncertainty to be a major theme in their QL study, which aimed to explore the psychosocial problems and management of 24 CRC patients with varying degrees of illness (Duke's A to D) (Browne et al., 2011). In-depth interviews were conducted with participants at diagnosis and one year later by the same researcher to ensure continuity. The researchers found that uncertainty was described in relation to; surgery, recurrence and spread of the disease, treatment, death and the impact of the illness on their families. The longitudinal design of this study allowed the processes associated with uncertainty to be explored with 19 of the original 24 participants, and the researchers found that one year later participants feared that the disease would return (Browne et al., 2011). In light of Sjovall et al (2011) and Browne et al's (2011) findings this study will consider how uncertainty is represented for the participants and how it changes over time.

2.3.3.1 Seeking and maintaining normality

In response to feelings of uncertainty, Shaha and Cox (2003) suggested that patients sought the routines and behaviours that they enjoyed before the cancer – they wanted normality to be restored (Shaha et al., 2008). The authors claimed that in response to contemplating their mortality, participants questioned their usual beliefs and relinquished control. In order to move forward in terms of their psychological response to illness, Shaha and Cox (2003) found that their participants had to regain control and find normality in their lives. So, according to the authors, returning to normality was a step towards achieving 'Dasein' – being in the world. Akin to Shaha and Cox (2003), Sjovall et al (2011) identified 'striving for normality' as a theme in their research. Their participants tried to counteract the limitations caused by the cancer by acting normally and thus 'reducing the space taken by the disease' (Sjovall et al 2011: 393). Living their seemingly normal lives allowed participants to feel that they were defined by their own

identity, not as a victim of cancer (Sjovall et al., 2011). Likewise Kidd (2008) found that maintaining a sense of normality was important for CRC patients to cement their identity. Kidd's (2008) study explored the experience of self care for 11 CRC patients[6] for the qualitative aspect of her mixed methods study. She found that the participants conducted self-care to preserve their identity and maintain a semblance of normality in their lives (Kidd et al., 2008). Issues of illness and identity are discussed later in this chapter.

2.3.4 Sense of self

Both Taylor (2001) and Little et al (1998) found that their participants experienced a loss of sense of self; an important finding in a number of the papers I reviewed (Kidd et al., 2008; Hubbard, Kidd, & Kearney, 2010; Rozmovits et al., 2004). Taylor (2001) reported that the change participants experienced in terms of their physical wellbeing emphasised a change in their sense of self. This was supported by Taylor's (2010) later work which found that in the period after diagnosis and surgery, participants dissociated from their bodies resulting in feelings of disembodiment (Taylor, Richardson, & Cowley, 2010). The theme of restoring embodied control, where the participant returned to normal life, was the main finding of Taylor's (2010) QL study. As with many other studies in this review, the focus was on recovery; and the participants had early stage, curative disease. What happens in the case of those with advanced, metastatic and terminal disease? Are they able to restore embodied control and return to a normal life?

Furthermore, Little et al (1998) described two ways in which usually transparent phenomena in everyday life become apparent with a diagnosis of CRC. Firstly, the workings of the digestive system become a conscious occurrence in the face of a social taboo, and secondly, the diagnosis of a serious illness (cancer or other) illuminates one's relationship with the self in the face of mortality (Little et al., 1998). The increasing

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[6] Refers to the actions taken by individuals to promote a fit and healthy body and mind (Kidd, Kearney, O'Carroll, & Hubbard, 2008).

visibility of such phenomena potentially compromises re-embodiment as it was described by Taylor (2001).

Little et al (1998) reported the findings of their narrative study which explored the experience of CRC in patients who had received surgery to remove the bowel. The narrative approach which was used in the study was thought to be ideal for exploring the subjective illness experience and as the authors commented, "it (narrative) is such good raw material" (Little et al., 1998: 1486). The authors used their own medical experience, published narratives, narratives in the media, and informal discussions with patients and former patients to inform the narrative interviews which they subsequently conducted with ten patients who had received a colectomy[7]. Three main themes were identified: 1) 'Cancer patientness' resembles Frank's (1995) notion of the cancer patient being a member of the 'Remission society' - where the diagnosis of cancer results in them being identified as a cancer patient. 2) 'Communicative alienation' refers to patients' inability to communicate their cancer experience with others and encompasses social isolation and loss of self. 3) 'Boundedness' refers to the way in which the social world "contracts" for sufferers and the way in which they develop a heightened awareness of their spatial and temporal limitations (Little et al., 1998).

Browne et al (2011) and Sjovall et al (2011) also concluded that the physical constraints of the cancer impacted on the participants' ability to socialise – in particular both articles commented on the challenges that participants faced when returning to work (Browne et al., 2011; Sjovall et al., 2011). Likewise Rozmovits and Ziebland (2004) found that participants with CRC experienced a loss of professional identity and the confidence to socialise – both of which are considered to be key aspects in the lives of functioning adults (Rozmovits et al., 2004). Their study was undertaken to consider aspects of distress for CRC patients and how the diagnosis impacts on identity and self-understanding for 39 participants. The authors ground their work with three key

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[7] Removal of the bowel because which results in a permanent stoma.

theories; 1) Elias's (2000) work on the Civilising Process[8]; 2) Mary Douglas's work about the inability to separate the physical and social bodies and the social disruption caused by illness (Douglas, 1985; Douglas, 1982); 3) Lawton's (2000) anthropological work carried out in a South East London hospice where she describes the unacceptability of the unbounded body in death (Lawton, 2000).

Rozmovits and Ziebland's (2004) study reflected a wide age range (33 to 87 years) and included those who were considered as palliative, which improves the applicability of this study to my own. Rozmovits and Ziebland (2004) generated data through narrative interviews, where the participants were given the opportunity to tell their own stories and thus prioritise what they wanted to share with the researcher. It is a strength of this study that the data reflects the participants' issues as they wished them to be known rather than necessarily reflecting the pre-ordained assumptions about what is important to the patient with CRC.

In terms of their relations with others, the altered sense of self that patients with CRC experienced led to altered relationships and, according to Browne et al (2011) and Rozmovits and Ziebland (2004), affected their ability to socialise (Browne et al., 2011; Rozmovits et al., 2004). Patients with CRC worried about becoming a burden as they became increasingly dependent upon others to help them function. Indeed Rinaldis et al (2009) found that social support was the only subscale on their measure of coping that consistently improved QoL over time for patients with CRC (Rinaldis et al., 2009). Using the findings from Dunn et al's (2006) qualitative study that is described above,

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[8] The Civilising Process by Elias (1978) describes how the body became civilized. Nettleton gives a helpful summary of Elias's work citing that there are three stages to the process of civilisation; 1) Socialization, where the body is considered in a social way rather than in its natural way and where natural process (such as defecation have become disgusting as opposed to natural). 2) Rationalisation where we have learnt to control emotions. 3) Individualization where we perceive our bodies as individual therefore we give each other space. This civilising process is compromised in illness and perhaps even more compromised with an illness relating to the bowel (Nettleton, 2006; Elias, 2000).

Rinaldis and colleagues (2009) developed and validated a measure of coping in 1800 CRC patients. The large numbers and longitudinal nature improved the rigour of this quantitative study. Browne et al (2011) also found that support from partners was a key element both at the time of recruitment, and a year later.

2.4 Caring for someone with advanced CRC

A recent paper by Murray et al (2010) suggests that those who are caring for a loved one who has lung cancer and is at the end of their life, suffer a similar trajectory of psychological and social decline as the patient themselves (Murray et al., 2010). The carers experienced social isolation and they had to give up their hobbies, work and sometimes holidays to care for the patient. Moreover the carers experienced uncertainty in the same way that the patients did. Similar experiences were described in the CRC literature although it was weighted to the experiences of spousal carers rather than offspring or sibling carers.

2.4.1 Psychological distress in caregivers

Houldin (2007) described that participants in their qualitative study of 14 carers of those with advanced CRC reportedly suffered from psychological distress in that they experienced anxiety, depression, guilt, anger (Houldin, 2007). Cotrim and Pereira (2008) support this as they too found that the caregiving role had a major impact on psychological morbidity and people experienced anxiety. This anxiety was exaggerated if the person with CRC had a stoma (Cotrim & Pereira, 2008). Houldin (2007) also found that there was a physical impact of caring as the participants described decreased appetite and poor sleeping (Houldin, 2007).

Feelings of helplessness were associated with the caregiving role (Houldin, 2007; Northouse et al., 2000; Sjovall et al., 2011; Emslie et al., 2009). Sjovall et al (2011) included carers in their study and they found that the carers felt 'shut out'. In addition to feeling helpless and frustrated, the carers in Sjovall et al's (2010) study highlighted the

importance of their social network; which is a concerning finding in light of the number of studies describing that carers also experience social isolation. For example Houldin (2007) found that the carers experienced a constricted social life and work life just as Rozmovits and Ziebland (2004) described of those with CRC, which also supports Murray et al's findings (Houldin, 2007; Rozmovits et al., 2004; Murray et al., 2010).

2.4.2 Adjusting to the caregiving role

Carers experienced changes in their relationship as they adjusted to the caregiving role and while their spouse or partner adjusted to the disease (Sjovall et al., 2011). The caregiving role was found to have a negative effect on the relationship between the patient and career because there was reduced intimacy and the carer felt burdened. Communication between partners also suffered for Sjovall et al's (2010) participants because they were unable to discuss the future as it took on a new meaning after the diagnosis (Sjovall et al., 2011). This echoes the findings of Houldin (2007) whose participants described being unable to make plans for the future – a subtheme in the domain entitled 'experiencing total disruption' (Houldin, 2007).

Caregiving could also have a positive impact on the relationship if patient and carer felt that their relationship was strengthened, and that they were more bonded (Houldin, 2007; Emslie et al., 2009). Sjovall et al (2010) and Taylor (2008) also described that the carers felt they were doing something valuable which was seen as a positive experience of the carer role (Sjovall et al., 2011; Taylor, 2008). Emslie et al (2009) reported that reciprocity was fundamental to the supportive relationships that CRC patients described - patients with CRC supported their partners like their partners supported them. Emslie et al (2009) conducted a secondary analysis of 33 interviews with married or co-habiting CRC patients. The data for Emslie et al's (2009) secondary analysis was from the research study by Rozmovits and Ziebland (2004) which was described in detail earlier in this chapter (page 21). Although the carer's own voice was missing from this study as they examined solely the patients' views on the caregiving role, it was interesting that

the authors noticed traditional gender roles were evident throughout the interviews. For example women tried to continue their normal household duties, sometimes to the detriment of their health whilst men sought to protect their loved ones with a stoical attitude towards their illness (Emslie et al., 2009). Having said this, the authors also made it clear that both men and women saw the importance, and likewise, valued the practical and emotional support from their partners which supports the findings by Browne et al (2011) and Rinaldis et al (2009).

One of the main themes to emerge from Houldin's (2007) study was that the carers felt they had to remain positive for their loved one, for themselves, and for their family (Houldin, 2007). It would seem that this 'emotion work' as Emslie et al (2009) described it was a reciprocal activity which patients and carers alike hoped would allow them to retain a semblance of normality for their families. In this way, both the carers and those they are looking after, take on the role of protector (Emslie et al., 2009; Houldin, 2007; Sjovall et al., 2011).

2.5 Dying from CRC - Psychological, social and spiritual wellbeing

As this literature review has demonstrated, few studies explored the experiences of those with advanced CRC (Sjovall et al., 2011; Houldin et al., 2006; Browne et al., 2011). As a result this section is also informed by the wider literature on death and dying. Given that Simon et al (2008) found that those with advanced disease have poorer psychosocial outcomes than those with early Duke's stage disease this is a rather alarming finding. Simon et al (2008) found that those with advanced disease had poorer outcomes in the following areas; QoL, anxiety, depression, social support, physical, functional and emotional wellbeing, and moreover, they felt less satisfied with medical interactions (Simon et al.e, 2008). This quantitative, questionnaire based study compared the Duke's stage of CRC with the responses from questionnaires from 128 people who had been diagnosed with CRC in the past year. Although the total number of participants was

small, and only 11 (8.6%) participants had advanced disease, it is a stark finding. This PhD study may contribute to understanding Simon et al's (2008) findings.

Anxiety and depression were commonly described in the end of life literature. For example, Murray et al (2007) found that participants with lung cancer who were in the last year of their life experienced psychological distress at key times in the illness trajectory using a qualitative longitudinal interview approach. Psychological distress was evident at diagnosis, after treatment, and as they made the transition to the terminal phase (Murray et al., 2007a). Fluctuations in spiritual wellbeing occurred in a similar way to the psychological distress as participants suffered gradual social decline and sought meaning in their lives (Murray et al., 2007a). Sjovall et al (2011) and Houldin and Lewis (2006) also described that participants with CRC became conscious of life's value as the illness progressed (Sjovall et al., 2011; Houldin et al., 2006).

Using a similar QL interviewing approach to Murray et al (2007), Nissim et al (2009) researched the desire for a hastened death in people with advanced lung and gastrointestinal cancers. They conducted 54 interviews with 27 participants who expressed a low or moderate desire for a hastened death based on questionnaires from a larger quantitative study that the participants were also involved in. They found that this desire occurred under three distinct, but not mutually exclusive, categories (Nissim et al., 2009).

1) The first, most common and most persistent category was desire for a hastened death as a hypothetical exit plan. This was not described as a current option for the participants; rather it was an option for the future when there were no other options left to them. Nissim et al (2009) describe it as a safety net for those who were terrified of the dying process.

2) The second category was desire for a hastened death as an expression of despair – In comparison to the first category this was transient, and was felt when participants were overwhelmed by feelings of helplessness, despair and panic. Moreover this was triggered by transitions in the illness trajectory. For example it was described

retrospectively at the time of diagnosis; when awaiting medical appointment; when the participants received disappointing results, or when their physical condition declined.

3) The final category is desire for a hastened death as a manifestation of letting go, which was only evident for those who were interviewed in the few weeks before death. The authors cite that this was understood in the context of a general disengagement from life and when compared with the earlier categories it was not seen as an explicit desire, instead it was acknowledgement that death was drawing closer (Nissim et al., 2009).

Feeling like a burden to others has also been described as an issue for those with cancer who are approaching the end of life (Chochinov et al., 2007). In this quantitative study by Chochinov et al (2007), 211 patients with advanced cancer who were expected to survive less than six months were recruited to examine 'burden to others' and how it related to psychosocial, physical, and existential issues. The results of the questionnaires suggest that burden to others was felt by 60% of the sample and that it was significantly correlated with hopelessness, depression, and outlook (Chochinov et al., 2007).

Lin and Bauer-Wu (2003) also describe hopelessness which was found to detract from the psycho-spiritual wellbeing of patients at the end of life. Lin and Bauer-Wu (2003) explored the research on psycho-spiritual well-being for those with advanced cancer. In addition to hopelessness they found that an awareness of prognosis was a key component of psycho-spiritual wellbeing, although this has also been known to cause distress (Payne et al., 1996). Others included coping and adjusting to stress, feeling connected to others, sense of faith, sense of empowerment, and living with meaning and hope (Lin & Bauer-Wu, 2003), which resonates with Murray et al's (2007) later work.

Although only a few papers described the psycho-social impact of living with terminal advanced CRC (Simon et al., 2008; Sjovall et al., 2011; Houldin et al., 2006), the literature suggests that participants with different types of advanced cancer may experience similar psychological, social, and spiritual, decline and distress (Murray et al., 2007)

2.6 Summary of the CRC literature

The literature suggests that in response to being diagnosed with CRC, patients feel a loss of control in terms of their physical and psycho-social and spiritual wellbeing. Making sense of the diagnosis is the first step to regaining control. Feelings of uncertainty were reported at every stage of the illness trajectory (Browne et al., 2011) and, in response to this, participants tried to restore normality to their lives. Those with advanced CRC experience psychosocial and spiritual distress as they approach the end of life, as do those caring for them at home. In addition to this, disrupted identity and a loss of sense of self were reported in a number of studies. It is with these latter two findings and the theories biographical disruption (Bury, 1982) and narrative reconstruction that I now turn.

2.7 Theorising the illness experience

Contemporary medical sociology poses two major categories for understanding the experience of illness. The first, Bury's (1982) theory of biographical disruption, and the second, narrative reconstruction (Williams, 1984; Bury, 1982). An increasing wealth of literature on these categories is available within a variety of social science and biomedical disciplines. I wish to draw upon this body of literature for a number of reasons. Firstly the CRC literature that I discussed above highlighted that loss of sense of self and issues of identity were common for CRC patients and indeed Hubbard et al (2010) found that some CRC patients suffered biographical disruption. Secondly, as the quote at the beginning of this chapter suggests, those with illness make sense of and understand their experiences by telling stories and thus I address narrative reconstruction and the history of narrative inquiry as a methodology for research.

2.7.1 Biographical disruption

Bury's (1982) theory of biographical disruption was conceived as a result of his work on the experience of rheumatoid arthritis (RA) (Bury, 1982). Bury recruited participants who were at an early stage on the illness trajectory, indeed some were recruited even

before they had received a confirmed diagnosis. Bury contends that in addition to disrupting the physical being, illness disrupts taken-for-granted aspects of daily life and the ill person's relationship with the self and with others (Bury, 1982). In fact by interviewing those who did not have a confirmed diagnosis Bury (1982) found that even the threat of illness is enough to cause disruption. Evidence of disruption to the taken-for-granted aspects of life were seen in the CRC literature, for example patients and carers felt unable to plan for the future in the same way they had prior to the diagnosis (Sjovall et al., 2011). Likewise, the CRC literature also suggests that patients felt that their sense of self was compromised and their relationships had altered, which resulted in social isolation for some (Kidd et al., 2008; Hubbard et al., 2010; Rozmovits et al., 2004).

Bury (1982) highlights three aspects of biographical disruption; 1) the disruption of commonplace assumptions and behaviours; 2) the disruption of an individual's explanatory mechanisms for coping; 3) the 'mobilisation of resources' that are required for the person to re-establish their biographical flow. Bury (1982) cites normalisation as a way of confronting altered relationships and embarrassment about their illness. Evidence of normalisation was also observed in the CRC literature and was described earlier in this chapter.

Bury's (1982) theory of biographical disruption has been subject to criticism in the last three decades as academics have questioned its applicability to other illnesses. For example, Williams (2000) questioned the relevance of Bury's (1982) theory for understanding the illness experience in a diverse 20th century Western society, although he praised Bury (1982) for his contribution to contemporary sociology and for giving a voice to an community that is often unheard (Williams, 2000). Williams (2000) argued that Bury's (1982) theory of biographical disruption failed to acknowledge how an individual's biography has already been shaped by the life they have led (for example children who are born with congenital anomalies or who become ill in early life). Accordingly Williams claimed that it cannot and should not be used as a standardised

theoretical framework, rather biographical disruption must be considered in light of the meaning and context of illness (Williams, 2000).

Williams (2000) concerns echo that of Pound et al (1998), who questioned the applicability of Bury's (1982) work for those who were older and who had previously suffered illness, or those whose lives had been disrupted by events which 'had led them to question the foundations and trajectories of their lives' (Pound et al., 1998: 491). The aim of Pound et al's (1998) study was to explore the experience of stroke in the context of the participants' lives. Forty stroke sufferers were interviewed ten months after the event to hear their stories. Pound and colleagues (1998) recruited the participants from the East End of London; a deprived area but with a real sense of community. The authors concluded that the experience of stroke in this East London community was not as 'disruptive' as had been previously described by Bury (1982). Pound posits two reasons for this. The first is that the participants may have been 'normalising' the illness in a stoical manner, and the second is that their age and previously difficult, and sometimes traumatic, backgrounds meant that their biographies were already disrupted and, as a result, the stroke was seen as a normal part of aging (Pound et al., 1998).

The geographical context of Pound et al's (1998) work is important as it finds support in the seminal ethnographic work of Jocelyn Cornwell, whose study was conducted in East London (Cornwell, 1984). Cornwell (1984) researched the health beliefs of 24 individuals; 15 women and 9 men. However her work was carried out on the premise that in order to understand people's assumptions about health and illness the context of their lives had to be taken into account hence the ethnographic, case study approach. Cornwell (1984) found that her participants constructed three types of illness.
1) 'Normal' illnesses such as infections that people are expected to get. 2) 'Real' illnesses - described as life-threatening diseases, where the reality of the illness was determined by the prognosis. 3) Health problems - which were associated with aging and the reproductive system, and were considered natural and often thought to be non-treatable by medicine (Cornwell 1984). Faircloth et al (2004) supports Pound et al's

(1998) findings in that stroke was seen by US Veterans as a normal part of aging. Although limited by the predominantly male sample (55 of 57 participants were male) of veterans the authors highlight the importance of individuality in response to illness. Therefore they report that the level of disruption may depend on the 'biographical contingencies of individuals' (Faircloth et al., 2004: 244).

Carricaburu and Pierret (1995) also contributed to Bury's (1982) theory of biographical disruption following their research into the experiences of Human Immunodeficiency Virus (HIV) infected men (Carricaburu & Pierret, 1995). The study comprised of two groups of men with HIV; the first group contracted HIV from homosexual activity and the second from infected blood transfusions which they required for haemophilia. The authors reported that some participants in the haemophiliac group experienced biographical disruption, particularly if they had denied the haemophilia, yet others did not. For those that did not experience biographical disruption, neither was the HIV considered a 'normal' illness like Pound et al (1998) and Faircloth (2004) described of stroke. All the participants in the homosexual group experienced biographical disruption when they were diagnosed with HIV. The commonality between the two groups was how the participants subsequently embarked on 'biographical reinforcement' which Carricaburu and Pierret (1995) define as,

> 'a reinforcement of their identities on the basis of what they had been before the infection' (Carricaburu et al., 1995:80)

Recent advances on the theory of biographical disruption suggest that context is important; for example co-morbidities, traumatic lives, a strong sense of identity and indeed, in some cases, illness may be considered as a normal part of aging. So how does cancer fit this theory? CRC affects people of all ages and can exist in the presence of a previously non-diseased body. Moreover there is a cultural imperative towards cancer which promotes survivorship, as the overwhelming propensity to focus on survivors in the literature suggests. Most people know someone who has survived, or died of cancer which inevitably influences their own experience and may or may not give them better

'biographical contingencies' with which to confront the disruption caused by their own illness (Faircloth et al., 2004).

In the context of CRC, Hubbard et al (2010) conducted a secondary analysis of the interviews to look specifically for evidence of biographical disruption (Hubbard et al., 2010). The 18 participants were interviewed three times in the year which followed their diagnosis, which meant the process of disruption could be explored. The researchers conducted two stages of analysis; in the first stage, the authors used the constant-comparative method to generate themes and, in the second stage, they further analysed the transcripts to identify biographical disruption as described by Bury (1982). The findings suggested that biographical disruption was evident for participants with CRC in response to threatened identities and that biographical work was carried out to restore this disrupted identity. Normalisation strategies such as going to work, doing household chores and enjoying social activities were evident as a means of retaining participants' pre-illness identity. This is consistent with the findings of the body of CRC literature which I reported above. Hubbard et al (2010) also suggest that such strategies may allow participants who are dying to maintain a sense of identity in death, although their study participants were followed for the first year after diagnosis so this area requires further exploration.

Exley (1999) similarly proposed that dying involved an irreversible change in an individual's sense of self, thus, those who are dying are required to find a way to preserve their identity for as long as possible. Exley (1999) recruited 19 participants from a hospice for her QL study which aimed to explore the experience of dying from cancer from the dying person's viewpoint (Exley, 1999). She specifically wanted to explore the experiences of those under 65 and used a life history approach when conducting the longitudinal interviews. This allowed her to focus on how the participants' experiences changed over time.

Exley (1999) found that participants sought to minimise the space that was consumed with dying in order to maintain their identities: a similar finding to that of Sjovall et al (2011) who described that maintaining normality decreased the time spent thinking about the illness (Sjovall et al., 2011). Participants in Exley's (1999) study did this through 'emotional work', which included planning for the time after their deaths. Likewise they grieved and helped their families grieve which, according to Exley (1999), meant they were negotiating an after-death identity for themselves. Exley's (1999) study also contributes to the notion of embodiment, as she suggests that in order to negotiate an after-death identity a person has to separate body and self (Exley, 1999).

Exley and Letherby (2001) continue with the idea of emotional work in a paper which aimed to: 1) View the impact of childlessness/infertility and terminal illness on everyday life and relationships and 2) Consider the link between the 'diagnosis' and emotion work (Exley & Letherby, 2001). The paper reflects the combination of two separate studies; the first consisted of a group of individuals with terminal cancer who had been referred to a hospice and were dying prematurely (Exley (1999) - which is described above) and the second, a group who described themselves as infertile or involuntarily childless. The authors found that terminal illness disrupted the natural life course of individuals through changes in their self-identity and in their relationships. This supports Bury's (1982) theory of biographical disruption. The participants in both groups faced challenges in their relationships; they did not want to be defined by the diagnosis or constantly reminded of it, but neither did they want to be 'strangers' or 'outsiders' in the lives they had before the disruption. Participants acknowledged that the social norms in everyday life thwarted the discussion of grief and illness more generally which presents a challenge for those coping with illness. Moreover, the authors suggest that individuals directed and articulated their experiences for different audiences which suggests the presence of multi-dimensional identities (Exley et al., 2001). The longitudinal nature of this PhD will allow me to explore changes to an individual's identity, hereby contributing to this body of knowledge.

2.7.2 Illness Narratives

Illness narratives are now considered to be more than mere representations of experience. Frank (1995) even suggests that the social construction of illness is the accumulation of illness narratives (Frank, 1995). The literature suggests that illness narratives have two main purposes. The first has its focus with the individual, where narratives help those suffering to make sense of their illness – narrative reconstruction. Through narrative reconstruction sufferers can give meaning to the illness and restore the identity that has been threatened by illness, which this literature review has demonstrated is commonplace. The second has a focus on society where the study of narratives provides an understanding of illness.

2.7.2.1 Narrative reconstruction

> "In the end, they (illness narratives) are more than just 'stories' but the vehicle for making sense of, not an illness, but a life." (Mathieson & Stam, 1995:284)

This quote from Mathieson and Stam's (1995) paper entitled 'Renegotiating identity: Cancer narratives' encompasses the very essence of narrative reconstruction. The authors explored how narratives were used to construct identity by interviewing 37 participants with cancer. The group ranged in age from 26 to 77 years and they suffered from a variety of cancers at a variety of stages (early; midrange with no metastases; and advanced). The interviews consisted of open ended questions which were specifically designed to tease out issues pertaining to identity. Using the constant-comparative method of analysis the authors identified that their participants' old narratives were challenged by the diagnosis of cancer thus they had to construct new narratives to incorporate the meaning of cancer in their lives (Mathieson et al., 1995).

Moreover Mathieson and Stam (1995) found that the participants' narratives were conceptualised using three themes. 1) 'Disrupted feelings of fit' – this theme was characterised by the threat that illness posed to a person's identity. For example, changes to a person's physical status, and their introduction to the health care system,

threatened their identity. 2) Renegotiating identity – this theme was associated with issues of stigma, and the authors also described the struggle that participants faced in finding their voice within the discourse of medicine. 3) 'Biographical work' – this theme describes how participants re-negotiated their lives after the cancer (Mathieson et al., 1995).

Mathieson and Stam (1995) pay homage to Arthur Kleinman, one of two seminal authors who advocate the therapeutic value of illness narratives; the second is Arthur Frank. Kleinman's experiences as a physician have allowed him to appreciate the power of storytelling. In the prologue to his seminal work entitled 'The Illness Narratives; Suffering, Healing and the Human Condition' (1988), Kleinman (1988) details an experience he had as a medical student. He was responsible for holding the hand of a young girl who had suffered severe burns which required daily cleaning in a bath. Having attempted several strategies to distract the young girl from the tremendous pain she was experiencing, Kleinman (1988) eventually asked her to tell him what is was like to suffer such an ordeal every day; to describe the pain she felt. The girl stopped screaming and stopped trying to fight the procedure and Kleinman (1988) concluded,

> "that it is possible to talk to with patients, even those who are most distressed, about the actual experience of illness, and that witnessing and helping to order that experience can be of therapeutic value" (Kleinman, 1988: xii)

According to Kleinman (1988), personal narratives result from of the patient's attempt to order their illness experience and consider what it means to them and to their significant others. This method of reordering their experiences and recapitulating events can provide clarity for individuals – again alluding to the capabilities of narrative reconstruction (Kleinman, 1988).

Frank's influential text entitled 'The Wounded Storyteller: Body, Illness and Ethics' (1995) is based upon Frank's own experience of illness, in addition to a collection of

narratives from fellow sufferers of illness[9]. The quote at the very beginning of this chapter emphasised the power of storytelling for those suffering from illness. Embedded in a debate about the ethics of storytelling, Frank (1995) presented a useful typology of illness narratives. Frank (1995) argued that concealed beneath the individual accounts of illness that sufferers narrate there are three general storylines.

Firstly there are narratives of restitution – they are the most commonly narrated story. Such narratives can only be told by survivors; those who will recover from illness and be well again, and they are the culturally sensitive stories that people want to hear. For those suffering from illness, the restitution narrative is a way of returning to normal after the disruption caused by illness and there has to be a belief that there is a future that is free from illness. Frank (1995) describes that the limitation of the restitution narrative is that it does not confront the issue of mortality which, as was seen in the uncertainty section of the review above, is a concern that is voiced by CRC patients.

Secondly, there are narratives of chaos which represent stories that are beyond speech. These stories can only be told retrospectively, when the sufferer is able to reflect on the events of the past. They are culturally unacceptable, hard to listen to and often provoke anxiety. Frank (1995) describes the chaos story as the anti-narrative; it is hard for the listener to understand due to the staccato nature of the words and the lack of temporal sequencing and, accordingly, it implies a feeling of being out of control.

Thirdly there are narratives of quest – where the reconstruction becomes evident. In narratives of quest those who have suffered confront their illness and find a positive use for it. According to Frank (1995) the quest narrative has three facets. 1) The memoir is a

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[9]Arthur Frank (1995) describes himself as the wounded storyteller. In 1985 he suffered a heart attack and as he was nearing recovery he discovered changes which proved to be testicular cancer. Frank (1995) describes his text as,

> "a survival kit, put together out of my need to make sense of my own survival, as I watch others seeking to make sense of theirs" (Frank, 1995: xiii)

combination of the author's illness and life story[10]. 2) The manifesto is more political than the memoir and is based on the notion that society suppresses illness. 3) The automythology uses the metaphor of the Phoenix who reinvents itself to create a more personal, less political, account of the illness experience.

Like Kleinman (1988) before him, Frank (1995) highlighted the importance of narratives in making sense of, and restoring, a sense of self after the devastating effects of illness. However useful, Frank's (1995) typology neglected the experiences of those who are terminally ill or dying: what type of story are they able to articulate?

2.7.2.2 The study of illness narratives

Hyden (1997) describes that illness narratives are useful in that they can transform illness from an individual context to a social phenomenon and can explain and understand the illness process (Hyden, 1997). For these reasons, the study of illness narratives has gained popularity in the last few decades. However, the increasing popularity of studying illness narratives gave birth to a fundamental debate within contemporary medical narratology. Paul Atkinson launched the discussion in his controversial paper entitled 'Narrative Turn or Blind Alley?' in 1997. Atkinson, a sociologist, promoted the study of narratives for understanding experience, but nevertheless posed two major concerns (Atkinson, 1997). Firstly, Atkinson (1997) proposed that the study of illness narratives predating his paper lacked methodological and analytical rigour[11]. Atkinson (1997) suggested that there was a focus on storytelling rather than story analysis, which fundamentally compromises the methodological rigour of the author's work and thus the claims they assert. Secondly, Atkinson (1997) proposed that illness narratives are being privileged by authors such as Kleinman, Mishler and Frank for their therapeutic value, over and above their content and social

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[10] For example, John Diamond famously detailed his cancer journey and his impending death in his Saturday column of The Times newspaper.

[11] Arthur Frank's The Wounded Storyteller was published in 1995 so he is one of the accused.

context, which results in misuse and misrepresentation in terms of their meaningfulness (Atkinson, 1997).

The debate has been kept alive given that a number of authors have responded to Atkinson (1997). The first retort came from Arthur Frank in his paper entitled 'The Standpoint of the Storyteller'. In defence of Atkinson's (1997) critique, Frank (2000) argued that narratives are more than just 'data' for research; they have a purpose in and of themselves, and a therapeutic value, as I alluded to above. Frank (2000) argued that in telling the narratives themselves, narrators recapitulate their experiences and in so doing promote remoralisation after the demoralisation caused by illness (Frank, 2000; Frank, 1995). Moreover, Frank (1995) described narratives as fundamentally social; as they are told to someone, and cultural; as they are a learned behaviour within the discourse of medicine; therefore to a certain extent he agreed with Atkinson (1997) (Frank 1995).

Although Atkinson (1997) seemed impressed with Frank's typology of illness narratives that I detailed above, he was nevertheless committed to his argument that Frank's (1995) analysis in The Wounded Storyteller lacked analytical rigour and can therefore be described as a collation of narratives where commonalities have been identified (Atkinson, 1997). However, having read The Wounded Storyteller I would argue that Frank (1995) did not make false claims with what he proposed to do. Frank's hope for the book was to encourage the ill patient to move from being the passive 'victim' of disease "towards activity" (Frank 1995: xi). He did not to provide a standardised tool for categorising the stories of ill people.

In a similar vein to Frank (2000), Bochner (2001) responded to Atkinson in his paper entitled 'Narrative Virtues'. Although Bochner is not one of the authors to be critiqued in Atkinson's 'Narrative Turn or Blind Alley?' paper, he comes to the defence of Frank, Mishler and Kleinman having been subjected to similar scrutiny himself in the past. Bochner's (2001) reply to Atkinson was more aggressive than that of Frank, but it is

evident that he shares a similar passion for narrative inquiry, its therapeutic benefits, and the capability of generating data, as Frank. Bochner (2001) concluded that Atkinson's argument and approach to narrative inquiry is 'unmistakably macho,' likewise it is detached, unromantic, and unsentimental; all the things that he felt narratives are not (Bochner, 2001). He agrees with Frank (2000) that the analyst/interviewer/researcher is the co-creator of the story; as does Mishler (1986), which is in contrast to Atkinson's (1997) view. In light of these contrasting viewpoints, Bochner (2001) concluded that Atkinson (1997) missed the very essence of the narrative turn which he argued is a necessary shake up of old academic principles and makes contemporary the ancient tradition of storytelling (Bochner, 2001). Atkinson and Frank come from fundamentally different epistemic standpoints despite their shared disciplinary background. According to Frank, where Atkinson is concerned with methodology, Frank is concerned with ethics, and where Atkinson is concerned with the ill patient, Frank is concerned with the ill person (Frank, 2000).

2.8 Concluding remarks

In this chapter I evaluated and synthesised the empirical and theoretical literature relating to the experience of CRC. This literature largely focused on the experience of those who survived CRC so I also discussed some key areas of the death and dying literature. I also reflected relevant theories to describe the impact of illness more generally; namely biographical disruption and narrative reconstruction. Evidence of disrupted identities was also present in the CRC literature. Biographical disruption and narrative reconstruction are processes; they occur over time and thus provide an ideal platform for exploring the potential of the QL method.

Although the aim of this PhD study is methodologically orientated I hope to contribute to the existing body of knowledge on the experience of advanced CRC. The literature highlighted that those with CRC have to make sense of their illness in light of the uncertainty that enfolds them, which, according to Browne at al. (2011), stays with them

in some form all along the illness trajectory (Browne et al., 2011). Both Sahay et al (2000) and Taylor (2001) suggested that further research adopt a QL approach to explore how the experiences of those with CRC change over time (Sahay et al., 2000; Taylor, 2001) and although several studies have accomplished this (Browne et al., 2011; Ramfelt et al., 2002; Taylor et al., 2010; Hubbard et al., 2010; Kidd et al., 2008; Shaha et al., 2003; Beech et al., 2011; McCaughan et al., 2011; McCaughan et al., 2012), the substantive findings from this PhD study on the experience of advanced disease would 4add to the current body of knowledge.

CHAPTER THREE

Qualitative longitudinal research (QLR): An evolving methodology

3.1 Introduction

QLR has been described as a theoretical paradigm as it implies a particular way of knowing and understanding the social world through time (Neale & Flowerdew, 2003). It has an established role in social science disciplines such as anthropology, criminology, education, psychology, social policy, and sociology. Contemporary QLR is driven by a desire to understand not just what change happens, but how and why it happens in the socio-cultural context (Holland et al., 2006). According to Neale and Flowerdew (2003), QLR can capture the interplay between time and the cultural dimensions of social life, which is in contrast to quantitative longitudinal methods that depict time as a linear phenomenon (Neale et al., 2003). One of the major advantages of QLR is a nuanced understanding of life which evolves through time (McLeod & Thomson, 2009).

This literature review has been informed by several key texts which, collectively, have contributed to the evolution of the QL methodology over the last decade. In 2003, Jonny Saldana, a theatre researcher, published the only book which is dedicated to QLR entitled 'Longitudinal qualitative research: Analysing change through time' (Saldana, 2003). This text has been widely cited and Saldana has been praised for his detailed guide to QL analysis. His text is informed by his experiences with three QL studies. The first is the Theatre Response Study which was conducted between 1982 and 1997 to explore how children respond to theatre. The second was an educational ethnography conducted over 20 months with Nancy, a teacher. The third was with Barry, one of the children from the aforementioned Theatre Response Study, who Saldana continued to study and together, with Barry, wrote his life history which they latterly turned into a one act play (Saldana, 2003).

In 2006 Holland and colleagues wrote a discussion paper which was in part the driver for this ESRC funded PhD study. The paper incorporates a literature review and a consultation with relevant individuals in the social science community about the feasibility of conducting a large scale planned and prospective QL study. Furthermore, there have been three themed issues in social science journals over the last decade which have showcased substantive findings from a number of QL studies and reflected on the QL method itself. The first was in 2003 in the International Journal of Social Research Methodology and was the outcome of a seminar at South Bank University, London, where researchers using the method presented their work. The second focused specifically on the contribution of QL methods to social policy (Corden, Millar, & (Eds), 2007). The third was in Qualitative Research in 2012 and researchers from the Timescapes study reflected on the recent advances in QLR and how QL data have been used, archived, and re-used. The Timescapes study (2007-2012), an ESRC funded initiative, consists of a number of projects which have explored how family and personal relationships change over time. In addition to the wealth of substantive findings that were drawn from the Timescapes initiative, the broad aim was to promote QLR. Given the increase in the number of QL studies in the social sciences over the last decade the researchers could argue this has been achieved (Timescapes: An ESRC Qualitative Longitudinal Initiative, 2012).

When combined, the existing body of literature makes a convincing case for QLR when compared with cross-sectional QL studies for exploring the process of change. The aim of this chapter is to illustrate the advantages but also reflect on the practical and ethical challenges of the QL design. In so doing I define QLR in the context of this PhD and examine the various methods of generating and analysing QL data. I conclude this chapter by considering the application of QLR in health care research.

3.2 Defining QLR

The contemporary model of QLR incorporates a planned, prospective design which differentiates it from other models such as follow-up studies, mixed methods studies with a QL aspect and evaluation or tracking studies (Holland et al., 2006; Thomson, 2007b; Neale et al., 2003). Given the epistemological and methodological diversity within the disciplines that utilise QL methods, the definition and conduct of QLR varies (Holland et al., 2006). In spite of this diversity the key features of QLR are fairly well defined as time, duration, process, and change (Saldana, 2003; Holland et al., 2006).

There is unanimous agreement that longitudinal research is about exploring change and as Saldana (2003) succinctly suggests, the purpose of QLR is to describe change, if there is any, using qualitative data. It is this interconnectedness between time and change that is the unique aspect of QLR. As Saldana (2003) also argued, QLR is not simply about researching from A to B; it is about researching from A to B *through* time (Saldana, 2003). The latter example implies a process, whereas the former is reductionist by comparison. The changes that will occur (if any) are dependant on the context of the study, and Saldana (2003) proposed that due to this, flexibility, in terms of design, methods, and analysis, is essential (Saldana, 2003; Tomanovic, 2003). Moreover, Saldana (2003) and others warn of the possibility that no change may be identified meaning the researcher should confront their own preconceptions about change and let a definition of change (if there is one) emerge (Pettigrew, 1990; Saldana, 2003; Lewis, 2007).

Lewis (2007) defined four types of change that can be exposed through analysing QL data in evaluation research. 1) Narrative change shows how individual stories evolve over the course of the study in terms of events or interactions and "feelings, hopes, reactions, plans." 2) Change in the context of time when a story is retold and re-interpreted by the participant at later interviews. 3) Change is evoked as the researcher sees the participant more clearly over time. 4) There may not be any change as I mentioned above (Lewis, 2007). Lewis (2007) highlights the multi-faceted nature of

change (Lewis, 2007; Corden & Millar, 2007a) and as Pettigrew (1990) suggested, the concept of change is in itself a process. Pettigrew (1990) argued that given the process-based and multi-faceted nature of change, the causes and impacts of change across time can be explored. Thus, QLR is about the process of chang*ing* - not change as a one off event (Pettigrew, 1990).

The ESRC Discussion Paper by Holland et al (2006) focused on QLR as planned and prospective and thus I have adopted this contemporary definition for my PhD.

3.3 Capturing process and change

3.3.1 How long is longitudinal?

Saldana (2003) suggested that defining the length of a longitudinal study is difficult which is evidenced by the varying lengths of his studies (ranging from 20 months to 15 years) and those I have witnessed in the literature. Corden and Nice (2007) supported Saldana (2003), also claiming that there is no clear definition of the length of QLR (Corden & Nice, 2007b). Defining the length of a QL study is complicated by the fact that it is only by conducting the study that we can understand how long it will take for change (if any) to occur – which highlights the importance of a flexible research design. However Saldana (2003) argues that long does not have to be 'lonnnnnnng,' as the length of QLR is dependent on the context of the study and the theoretical paradigm. For example, if studying education, it may be appropriate to consider the school year, which is approximately nine months (Saldana, 2003). Another example of this is Taylor's (2009) study with vulnerable youths which was conducted over a period of four months and is an example of a short-term longitudinal study. Taylor (2009) justified the length by arguing that other studies have examined processes and change in the short term and perhaps more importantly she was keen not to lose her vulnerable group to follow-up (Taylor, 2009).

McLeod (2003) argued that they adopted a long time frame for the 12 – 18 Project, a study about Australian secondary school students, to allow participants to reflect back to earlier events and to have 'a sense of themselves in the long view' (McLeod, 2003: 205). However she also argued that a shorter time frame could still have captured change because in the life of an adolescent change can occur in a short space of time. One of the most famous QL studies is the television series '7 Up' by Michael Apted which has just celebrated its eighth series, '56 Up'. Apted started following a group of 14 British seven year olds in 1964 to understand how social class determined their future and he continues to interview those that wish to be included every seven years (Apted, 1999). Other 'lonnnnnnnger' studies include the Inventing Adulthoods study which was conducted between 1996 and 2006 in England and 1996 and 2010 in Northern Ireland. This impressive QL study followed 120 young people through six interviews into adulthood through a time of social and economic change. The researchers should be credited with the fact that they were able to maintain the same research team of five women for the entire time which ensured continuity in the research relationship, in analysis, and more recently in archiving the data for secondary analysis (Inventing Adulthoods, 2012).

3.3.2 Methods to generate QL data

In the same way that the 'how long' question is dependent on context, theoretical paradigm and discipline, so too is the question of how and when to generate data. One key facet of QL data generation is that it should be iterative - that it builds on previous waves of data collection to tell a story over time and to draw on what was learnt previously to understand what has changed (McLeod et al., 2009). For example, Lewis (2007) described how she summarised each interview using a Framework analysis prior to the next interview to build upon the narrative (Lewis, 2007). It is this iterative approach that convinces McLeod and Thomson (2009) that QLR is more than the sum of its cross-sectional parts (McLeod et al., 2009).

It is unsurprising that most of the studies that are referred to in this literature review adopted interviewing methods to generate data as they are commonly used for qualitative research. The methods used in QLR are similar to those used in cross-sectional qualitative research, however QLR is ripe for innovative, and multiple, strategies for generating data. Holland et al (2006) support the use of interviews, videos, written narratives, case studies and other visual methods of eliciting data. The 12 – 18 Project conducted by McLeod (2003) used interviews, photographs, tape recording and video-recording to generate data which highlights the range of possibilities (McLeod, 2003; McLeod et al., 2009). Like the 12 – 18 Project, the Inventing Adulthoods Project used a number of methods to generate biographical data including memory books (described as diary/scrapbook) and lifelines which included demographic data amongst other things (Inventing Adulthoods, 2012). With the increasing use of technologies in research, particularly in areas such as blogging and social media, there are potentially exciting opportunities for QL researchers.

3.3.3 Analysing QL data

According to Holland et al (2006), QL analysis triples the burden that already exists in qualitative research meaning it is extremely time consuming. However it presents many analytical opportunities which somewhat placates the issue of time spent. In light of this, organisation of the data is key (Holland et al., 2006). Some analysts advocate the use of data management software, such as NVivo to help handle the complex matrix of data. Holland and Thomson (2003) found that using a software package facilitated the recall of data based on particular assumptions such as age and gender. However Clandinin and Connelly (2000) refute this, arguing that such computer packages are unsuitable for handling huge volumes of data – such as those generated in QLR (Clandinin & Connelly, 2000).

There are three main directions of QL analysis –
1) Cross-sectional analysis at each time point

2) Across time analysis, across cases

3) Across time analysis, within cases (Holland et al., 2006).

It is this multi-dimensional analysis that is required to make full use of the wealth of longitudinal data (Lewis, 2007). However, as I hope to have emphasised throughout this chapter, the focus of the analysis is on change. To follow are just two examples to highlight the variety of approaches.

1) Saldana's (2003) prescriptive guide to QL analysis has been widely cited (Saldana, 2003). He posed 16 analytical questions, in three categories, to help the researcher organise the data. I have adapted table one (page 47) from chapters four, five and six of Saldana's (2003) text to provide an overview of these questions. Firstly there are the framing questions; these should be answered first to identify the context in which the analysis is being conducted. Secondly there are descriptive questions; these questions are iterative, should elucidate descriptive answers, and can be answered as they are needed, as opposed to being a linear checklist as table one (page 47) may suggest. The third set of questions are analytical and interpretive and they are posed to help the analyst "rise above the data" towards interpretation and theory generation (Saldana, 2003: 63).

There are two possible criticisms of Saldana's method. In his text, Saldana (2003) predominantly discusses grounded theory analysis and coding as the means of analysis. Firstly, it could be argued that Saldana's (2003) guide has limited applicability when using other methods of data generation and analysis, such as narrative methods where the aim is to keep the story as a whole and prevent de-fragmentation. Akin to this is that Saldana's (2003) questions guide the analyst through pools of data rather than through the data of one individual, which he himself confessed. This approach may not be appropriate for QL research projects which aim to follow individuals over time.

Framing Questions	What is different from one pool of data to the next?
These questions address and manage the contexts of the study data by locating them in a processual, 'analytic ocean'.	When do changes occur through time?
	What contextual or intervening conditions appear to influence and affect participant changes through time?
	What are the dynamics of participant change?
	What preliminary assertions about participant changes can be made as data analysis progresses?
Descriptive Questions	What increases or emerges through time?
To help answer the framing and analytic questions. These could as easily be statistical number answers.	What is cumulative through time?
	What kinds of surges or epiphanies occur through time?
	What decreases or ceases through time?
	What remains constant or consistent through time?
	What is idiosyncratic through time?
	What is missing through time?
Analytic and Interpretive Questions	Which changes interrelate through time?
This stage is towards richer levels of analysis. These are iterative and the answers may be revealed at any time/stage	Which changes oppose or harmonize with natural human development or constructed social processes?
	What are the participant or conceptual rhythms through time?
	What is the through line of the study?

Table 1. Questions to guide the analysis of QL data. Adapted from Saldana (2003) Chapters 4, 5, 6

2) The case profile method was devised by Thomson, Holland and the team from the Inventing Adulthoods study (Inventing Adulthoods, 2012; Thomson, 2007a; Thomson & Holland, 2003). The researchers wanted to understand the data both in cross-section and longitudinally and in so doing felt they were able to privilege the social and spatial context, and the individual context. They achieved this in three ways according to Holland and Thomson (2003).

i) Firstly the researchers conducted a narrative analysis after each interview which allowed them to understand both the overall story that was being told and the substantive content of the interviews. As the interviews accumulated, this became a 'case profile' for each participant where they could identify changes and continuities over time. This analysis incorporated the researchers' reflections on the participants' stories thus appreciating the interactive nature of the interviews.

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ii) Secondly the researchers moved 'from the narratives of individuals to the narratives of a community' (Thomson et al., 2003: 237) which Thomson (2007) later described as putting the case profiles in 'conversation with one another' (Thomson, 2007b: 575).

iii) Lastly the researchers conducted a descriptive cross-sectional analysis at each time point to understand a particular period in time. In doing this they felt they were able to offer comparisons across the sample in terms of age, gender, social class, and other demographic characteristics. This aspect of the analysis was carried out by researchers out with the research team, which would not be feasible in many short term QL studies due to financial and other restrictions.

Holland and Thomson (2003) concluded that both the longitudinal and cross-sectional approaches to QL analysis are not only necessary, but provided a coherent and nuanced understanding of both the individual and the community experience.

These examples from Saldana (2003) and Holland and Thomson (2003) illustrate just two of the ways in which researchers can approach QL analysis. Of course there are many more, but unfortunately there is a lack of transparency in the method of analysis within the literature. I have highlighted that the design, methods, and analysis, are dependent on the context of the phenomenon that is being researched. This is the case with all qualitative research, but QLR presents unique opportunities given the potential for flexibility and innovation. The aims, methods and analysis can be reviewed and revised as the study progresses in order to do justice to the huge wealth of data.

3.4 Practical and ethical challenges in QLR

Although QLR does not necessarily present new challenges for researchers, existing practical and ethical issues can be amplified when compared with one-off cross-sectional studies (Holland et al., 2006; Murray et al., 2009; McLeod et al., 2009). Indeed ethical issues featured strongly during the consultation for the ESRC Discussion Paper as

concerns were raised regarding consent, confidentiality, anonymity, intrusion, dependency, distortion of life experience through repeated intervention, emotional involvement, and problems with closure after the study has finished (Holland et al., 2006). In the section to follow I discuss some of these practical and ethical issues further and suggest how they might be overcome.

3.4.1 Overcoming the practical challenges

3.4.1.2 Data management

QLR studies are well known to generate huge volumes of data and as Lewis (2007) described,

"The volume of data is at once the delight and the challenge of QL analysis" (Lewis, 2007: 550).

Although a strength of the QL design, it also represents a challenge in terms of management, analysis and reporting. The key message from the literature is that organisation in managing QL data is imperative (Holland et al., 2006). Moreover, Corden and Nice (2007) suggested that researchers have an ethical duty to use the data as participants had expected it to be used (Corden et al., 2007b) meaning innovative strategies and rigorous organisation may be required to ensure clarity of the data that is generated (Holland et al., 2006).

Part of managing the data is disseminating it, and the question of how and when to report interim findings has been raised. Corden and Nice (2007) described the challenges they faced in reporting the interim findings of their research project to the stakeholders involved. They were cautious not to over-interpret the interim findings and as a result generate false enthusiasm; yet they still wanted to maintain positivity about the project (Corden et al., 2007b). The issue of when to disseminate QLR findings was also raised by Holland et al (2006), and the contributors to their discussion paper concluded that although researchers should publish as the study proceeds, they should also include a caveat that the findings are subject to change (Holland et al., 2006).

3.4.1.3 Minimising Attrition

Attrition is potentially more problematic in QL studies due to the temporal nature of the research. Corden and Nice (2007) described how they dealt with attrition in their QL study which was part of an evaluation of a pilot to reform incapacity benefits (Corden et al., 2007b). Their study was commissioned by the Department of Work and Pensions and commenced in 2003. Corden and Nice (2007) published both their experiences of conducting this QL study and the substantive findings in separate publications for inclusion in the Social Policy and Society special edition that was mentioned in the introduction to this chapter (page 41). Corden and Nice (2007) described how they lost six people from the original 24 after the first interviews – this was consistent in all three of their cohorts. They decided it was unethical not to use what data they had, particularly when those six participants had wanted their voices to be heard. Moreover, they decided it would be uneconomical not to use the data that had already been generated. So, rather than look for change prospectively since the study began, they decided to look for change since the pilot to reform the incapacity benefits began. By doing this they could include the data generated from the interviews with the six people who were lost to follow up as they had shared their experiences of the pilot reform. Corden and Nice (2007) illustrate the flexibility of the QL approach which Holland et al (2006) reported to be one of the major values of the design (Corden et al., 2007b; Holland et al., 2006).

A number of papers reflected on the strategies they used to minimise attrition and keep participants engaged, motivated, and in contact. This was particularly the case for the studies that involved those considered vulnerable (i.e. drug users and vulnerable youths). Although the groups of participants differ, there are lessons to be learnt from the researchers' experiences. For example, Taylor (2009) described five strategies that she felt contributed to the fact that she had no attrition in her study with vulnerable youths.

1) Screening

Taylor (2009) first screened potential participants. She spoke to them once on the phone and met them once face to face, at which time she invited them to decline participation by email or text should they wish. In doing this Taylor (2009) was trying to make it as easy as possible for participants to be involved in the study and she was deliberately giving them the opportunity to reflect on their meeting with her in private.

2) The first interview

Having already met with the participants on two occasions Taylor (2009) felt she was no longer considered a stranger which she felt had a positive impact. At the first interview Taylor (2009) opted to use a card sorting task where participants chose a card which best represented their feelings, the topics of which were based on the literature review. She hoped that this would maximise the youth's engagement with the process. She reported that the participants found this to be an interesting and non-threatening task. However, more importantly it differentiated the research interview from previous interviews they had undertaken with social services which, for some, had negative connotations.

3) Stipend

Taylor's participants received a stipend of $140 (approximately £100) for their participation in the research as an overt retention strategy. She believed that the stipend did not result in coercion for two reasons. Firstly she paid the participants at the beginning of each interview so they felt they could leave at any time yet the interviews still averaged an hour in length. Secondly the process of informed consent occurred on two occasion giving participants ample time to consider their participation in the research.

Taylor's (2009) study was carried out in California and in the United States of America (USA) where it is standard practice to pay subjects for participating in research. Having said this, Harocopos and Dennis (2003) reported giving their participants incentives for their participation in a QL study about the experiences of drug users in the UK. They

felt that these incentives 'professionalised' the research process from the perspective of the participants; especially since all the respondents were unemployed at the time of the first interview and 91% relied on illegally sought earnings to fund their drug habit (Harocopos & Dennis, 2003). Likewise, Watson et al (1991) provided money for their participants who were also drug users and found that they were occasionally 'hustled' by the participants to conduct the interview early so they could receive the money (Watson, Irwin, & Michalske, 1991). This raises issues about the welfare of the researchers in QL research which I will discuss in the section to follow. Paying people to participate in research, longitudinal or otherwise, is an ethical debate in itself − is it coercion, undue inducement or exploitation? (Dickert et al., 2002).

4) Interim phone calls

Taylor (2009) conducted interim phone calls with her participants to maintain contact meaning they could also tell her if they had moved or changed email address. Moreover Taylor (2009) found that the phone calls allowed events to be seen in real time which could then be discussed at subsequent interviews. Similar strategies such as Christmas cards, birthday cards and newsletters have been employed by other researchers to keep in contact with their participants (McLeod et al., 2009).

5) Self and researcher role

Lastly Taylor (2009) described how she felt her relationship with the participants had contributed to keeping them engaged. And it is with this issue of the research relationship that I will now turn.

3.4.1.4 The research relationship

As Taylor (2009) alluded to, the role of the researcher in qualitative research is widely recognised and written about, but this is emphasised in QLR, and as Holland et al (2003) suggest, the research relationship becomes an inevitable focus (Holland et al., 2006). Taylor (2009) sought to make her participants feel safe, empowered and heard and in so doing hoped a trusting relationship would evolve. One strategy that she employed to

achieve this relationship was not to give advice about work or education. This is consistent with her strategy to differentiate her interviews from those that the youths may have had with social workers or other professionals that I described previously. In fact a number of her participants commented that they found it refreshing to speak to someone who was there 'just to understand' (Taylor, 2009).

The notion that participation in QLR is an intervention in itself is a potentially contentious one and, as Thomson and Holland (2003) state, any predictions about therapeutic potential should be treated with caution. However, Thomson and Holland (2003) described how most of their participants found the study an enjoyable and unusual process and some even described it as cathartic. Their approach was that they were not explicitly making an intervention in the lives of the young people they interviewed but neither did they deny that they might be doing so. Thomson and Holland (2003) prided themselves on maintaining continuity in the Inventing Adulthoods study and they felt it fostered the best possible relationship with the participants (Thomson et al., 2003). As I hinted earlier they extended this continuity to the analysis phase of the project and more recently to archiving the data (McLeod et al., 2009). However, in order to ensure this continuity there needs to be a constant stream of funding which is an ongoing challenge in all research.

Taylor (2009) also described how she shared personal information with the participants when it was appropriate, a matter that she was unable to avoid as she was pregnant during the study – a fact that she felt humanised her in the eyes of the participants. Having said this, she also highlighted the importance of establishing boundaries and described how she felt unable to give a participant a lift in her car after an interview as she felt it would be inappropriate. Watson et al (1991) also reflected on the importance of boundaries, given that they had problems with infatuation from some of the male participants in their study with drug users.

Watson et al (1991), like Taylor (2009), found that being 'human' enabled a trusting relationship. Watson et al (1991) concluded that being uninvolved in QLR was an abstract notion. This means that how we reflect on our involvement as researchers makes rigorous qualitative research. Saldana (2003) supports this assertion claiming that the longer researchers are involved in QLR the more embedded they become, which highlights the importance of reflexivity. I will discuss my approach to reflexivity in chapter four. Such intense involvement can have repercussions for the welfare of the researcher (Saldana, 2003), and this may be exaggerated when working with particular groups such as children, adolescents, and drug users, as the experiences of Taylor (2009) and Watson et al (1991) suggested. In the context of this PhD study this could be extended to working with those with serious illness. Throughout this thesis I reflect both on my position in the research and on my thoughts and feelings as I became increasingly embedded in the relationship.

3.4.2 Overcoming the ethical challenges

3.4.2.1 Serial Consent

The process of informed consent is a necessity before any participant is recruited into a research project, but in QLR that consent requires constant re-negotiation (Murray et al. 2009). Participants may change their minds in the interim period between the waves of data collection meaning serial consent is essential. Holland et al (2006) highlighted that the process of consent is complicated by the fact that those participating in longitudinal studies may feel a sense of social responsibility and obligation to continue with the study over time (Holland et al., 2006; Taylor, 2009). Moreover the contributors to the discussion paper thought that in adhering to the true principle of informed consent participants should be told about any refinement to the aims and objectives that may be made as the study proceeds.

The issue of consent is interconnected with the issue of conducting QLR with potentially vulnerable groups. For example Saldana (2003), Taylor (2009), Thomson (2007) and

Ward and Henderson (2003) conducted research with youths – which they considered a vulnerable group (Saldana, 2003; Taylor, 2009; Thomson, 2007a; Ward & Henderson, 2003). Harocopos and Dennis (2003) and Watson et al (1991) conducted research with drug users (Harocopos et al., 2003; Watson et al., 1991). Taylor (2009) carried out consent procedures formally on two occasions, the first when she screened potential participants for the study, and the second prior to the first interview. Taylor (2009) screened potential participants prior to officially recruiting them into her study because she was worried about the psychological burden of their participation. It could be argued that in so doing she was silencing the voices of those whose voices needed to be heard but rather she argues that she was purposively sampling on ethical and welfare grounds. Taylor (2009) felt a sense of responsibility towards her participants (Taylor, 2009).

Ward and Henderson (2003) also felt a sense of responsibility for their participants following their experiences undertaking tracking research with youths who were leaving the care system, many of whom had endured a turbulent childhood (Ward et al., 2003). Although I am not likening those with serious illness and perhaps at the end of their lives with either of these groups, I do recognise parallels in terms of maintaining contact due to the often transient nature of their lives when they may be frequently in and out of the hospital or hospice.

3.4.2.2 Confidentiality and anonymity

Confidentiality and anonymity of longitudinal data is exaggerated insofar as there are more stories to paint a biographical picture of the participant's life over time. This is further complicated by the current drive to archive QL data for secondary analysis, meaning there is an increased risk of the data falling into the wrong hands. This highlights the need for organised and secure data management (Holland et al., 2006).

Thomson (2007) highlighted her concern that whilst producing in depth, longitudinal and nuanced accounts, cases may remain anonymous to the reader but may be recognised by the narrator (Thomson, 2007a). Rachel Thomson, a prolific author on

QLR methods reflected on the practical and ethical challenges of carrying out QLR to form case histories for the Inventing Adulthoods study in her paper entitled "The qualitative longitudinal case history: Practical, methodological and ethical reflections" (Thomson, 2007b). Thomson (2007) adopted a case history approach where she detailed the accounts of individuals. In an effort to counter concerns about misinterpreting the participants' lives she offered them a tape recording of their interviews after the third round so that the participants could understand the perspective of researchers. Although not all the participants listened to it at the time, they were given the opportunity later to read their case histories before they were published. In doing this, the researchers ensured the rigour of their research and felt they were maintaining the autonomy of their participants. It is the task of the researcher to negotiate a balance between managing the integrity of the research with the anonymity of the participant, as Thomson (2007) has described.

3.5 QL methods for health care research

I have witnessed the increasing popularity of QLR in health care research over the course of this PhD, but there are still relatively few studies when compared to cross-sectional qualitative studies. Possible reasons for this include; financial constraints from funders who privilege quantitative methods over qualitative; concerns about recruiting potentially 'vulnerable' people to longitudinal studies; and the epistemological difference between the social sciences and medicine insomuch as health care research remains a predominantly positivist discipline, where randomised control trials and cohort studies are thought to be the gold standard in terms of research methods. Having said this, qualitative research is growing in popularity given its capabilities for answering the 'how' and 'why' questions yet it remains that relatively few studies get published in major medical journals.

In 1990 Conrad highlighted the potential of QLR for the study of chronic illness. He noted that researchers often study process and change in chronic illness but to gain a

more accurate picture, participants should be followed up over time. Moreover he reflected on the benefit of conducting research on chronic illness over two or more years to enable a deeper understanding of the temporal notions associated with chronic illness (Conrad, 1990). The Primary Palliative Care Research Group at the University of Edinburgh recently published a paper entitled, 'Use of serial qualitative interviews to understand patients' evolving needs and experiences' which can be found in appendix one (page 288) (Murray et al., 2009). This paper was deliberately submitted, and published, in the British Medical Journal (BMJ) because our hope was to showcase the benefits of QLR for exploring the needs of patients with life limiting diseases to a mass audience of generalists working within health care research.

The potential benefits of a qualitative longitudinal (QL) approach for exploring the needs of people with progressive diseases have been highlighted in response to the complex, temporal changes that these patients experience (Murray et al., 2006; Murray et al., 2009). Indeed, Murray et al (2007) synthesised two QL studies to map the psychological, social and spiritual decline of patients with lung cancer and heart failure at the end of their lives (Murray et al., 2007a). Murray et al (2010) has since extended these trajectories to describe the archetypal trajectories of physical, psychological, social and spiritual decline of those caring for patients with progressive illness (Murray et al., 2010). Cavers et al (2012) described the experiences of patients with glioma, a malignant brain tumour and their carers (Cavers et al., 2012). Collectively, these studies illustrate the potential benefits of a prospective QL design for understanding the multidimensional experience of serious illness over time.

The aim of a review of the QL health care literature was to understand why and how the method was being used. A broad search of the QL health care literature identified studies in five main areas; cancer; end of life research; chronic illness (stroke, disability, renal disease, Parkinson's disease; HIV); diabetes; health education and informatics. Although diabetes would usually be considered a chronic illness there is a significant body of work which justified its inclusion as an area in itself. However, my interest lay

in *why* health care researchers used QLR and it is for this reason that I selected and evaluated studies which examined a *process* (for example, coping). Additional information was gathered to describe how the researchers carried out and described the methods of data generation and analysis, and if there was any discussion of the perceived benefits or challenges of the QL approach.

Table two (page 59) provides examples of the processes that were explored within the QL health care literature and how the authors explored them. The aim of this table is not to provide an exhaustive review of the literature; rather it is to provide an overview of the phenomenon which attracts a QL approach.

Process explored	Title of paper	Aim of paper	Methods			Rationale for QL design and reflections on the method
			Duration, time points	Data generation	Analysis	
Coping	Coping, meaning and symptom experience: A narrative approach to the overwhelming impacts of breast cancer in the first year following diagnosis (Tighe et al., 2011)	To explore the issues and means through which women relate their symptoms, treatments and effects and how women cope and make sense of the impacts of breast cancer on inter-personal relations and return to work	12 months, 4 time points 1) ASAP after diagnosis 2) 3 months 3) 6 months 4) 12 months	39 Interviews with 10 women with newly diagnosed breast cancer in their homes	Thematic narrative analysis. Using a case-centered approach to compare themes and patterns across, and within time.	The authors used the 'cancer journey' as the comparative unit of analysis. This enabled them to see how changes through time denote stages of crisis, recovery and transition in the context of relationships.
Distress	A longitudinal qualitative analysis of the factors that influence patient distress within the lung cancer population (Lowe & Molassiotis, 2011)	To examine lung cancer patients' symptom experiences and the explanatory models used by patients and caregivers To improve understandings of patient symptom experiences and distress across the disease trajectory	12 months, 4 time points 1) Beginning of treatment 2) 3 months 3) 6 months 4) 12 months	44 Semi-structured narrative interview with 16 participants with inoperable primary lung cancer	Interpretative phenomenological analysis which was tailored to larger data sets	The author's rationale for the QL design was that the relationship between QoL and distress does not stay constant over the illness trajectory thus it should be explored over time
The dying process	Confronting the prospect of dying: Reports of terminally ill patients (Yedidia & MacGregor, 2001)	To identify common themes which characterise patients' perspectives on death	An average of 4.2 interviews per patient as close to death as possible	Interviews with 30 patients with a life-threatening illness who were likely to die within 1 year	Inductive qualitative analysis to present a motifs which characterised how participants viewed the prospect of their own death	The authors concluded that the serial-interviewing approach facilitated an increased understanding of the frameworks by which individuals give meaning and consistency to the lives
Recovery, re-integration and rehabilitation	'Getting back to real living': a qualitative study of the process of community reintegration after stroke (Wood et al.	To examine this process of community reintegration after stroke from the patient's perspective	12 months, 5 time points 1) Predischarge 2) Two weeks 3) 3 months 4) 6 months 5) 1 year	Semi-structured interviews with 10 participants who were recovering and rehabilitating after a stroke	Grounded theory analysis where coding identified a core category and a longitudinal storyline	The authors report that the needs of stroke survivors change over the course of a year which – this may not have been captured with a snapshot approach

Process explored	Title of paper	Aim of paper	Methods			Rationale for the QL design and reflections on the method
			Study duration, time points	Data generation	Analysis	
Understanding /self management	Dose Adjustment For Normal Eating (DAFNE): A qualitative longitudinal exploration of the food and eating practices of type 1 diabetes patients converted to flexible intensive insulin therapy in the UK (Lawton et al., 2011)	To explore whether and why patients change their food and eating practices following conversion to flexible intensive insulin therapy	12 months, 3 time points 1) Baseline (after completing the DAFNE course) 2) 6 months 3) 12 months	Interviews with 30 participants, usually in their homes. The interviews were iterative and participant specific, building on earlier themes from previous interviews	The 3 transcripts for each participant were read consecutively to pay attention to continuities and changes and the reasons for these. Within respondent accounts were compared with between respondent accounts to identify overarching themes.	A QL approach was used to capture participants' understandings and experiences of managing their diabetes and any changes and continuities in their dietary habits as a result of treatment. QL design highlighted that over time participants made minor changes to their eating habits with flexible intensive insulin therapy.
Identity reconstruction	Toward a trajectory of identity reconstruction in chronic fatigue syndrome/myalgic encephalomyelitis: A longitudinal qualitative study (Whitehead, 2006)	To examine the reconstruction of self-identity for those experiencing chronic fatigue syndrome/myalgic encephalomyelitis (CSF/ME)	2.5 years, 3 time points	Interviews with 17 patients and their families in their homes	Analysis was iterative. Key words and concepts emerged and themes were generated.	The author reported that the QL method highlighted the significance of temporality for participants and that the longitudinal approach was appropriate for research which explored the evolution of identity reconstruction

Table 2. QL studies in health care which represent the range of processes, the methods used and the reflections on the method

As table two (page 59) illustrates, there are a variety of processes which have been explored over time, which highlight different aspects of the illness experience. These include coping strategies, distress, rehabilitation and recovery, the dying process, self-management and identity re-construction. Most of the studies were conducted over the course of a year with the exception of Whitehead's (2006) study of identity reconstruction in patients with CSF/ME. There were a few studies that exceeded a length of one year and were in the area of chronic illness. For example Graungaard and Andersen's (2011) study of emotions, coping and resource-creation when parenting a child with disability which was conducted over two years and Eilersten's et al's (2010) two year QL study about stroke recovery (Graungaard et al., 2011; Eilertsen et al, 2010).

Compared to the social science QL studies, the health care literature revealed no 'lonnnnnnngitudinal' QLR (Saldana, 2003). As Conrad (1990) highlighted, researching chronic illness is ripe for exploration over a longer period of time. This is particularly true when people are living longer, but with greater morbidity. However in some cases the shorter term QL design is appropriate. For example, when researching some processes, such as the experiences at the end of life which were generally conducted over a period of 12 - 18 months (Worth et al., 2009; Murray et al., 2002; Exley, 1999; Andershed & Ternestedt, 1998).

Most studies generated data from three or more time points, which is regular follow up when compared with some of the social science QL studies that I described earlier in this chapter. As table two (page 59) suggests, data was overwhelmingly generated from face to face interviews which is consistent with the body of QL health care literature on the whole. I identified a few studies that supplemented interviews with other methods, such as diaries, but Begley (1999) and Gray and Smith (2000) were researching the experiences of nursing students, so only Goodacre's (2006) study was about the experience of illness (Begley, 1999; Goodacre, 2006; Gray & Smith, 2000). Having said this, face to face interviews are beneficial as they allow researchers to assess verbal cues

from potentially unwell participants. I also identified three QL studies which used ethnographic methods, in addition to interviews (Graft Aikins, 2005; Harwood, Cohn, & Simmons, 2012; Woodgate & Degner, 2004; Lawton, 2000). For example, Woodgate and Degner (2004) conducted 960 hours of observation over the course of the study to gain a greater understanding of the cancer symptom transitions (Woodgate et al., 2004).

In-depth descriptions of the procedure of longitudinal analysis and reflections on the QL design were sparse in the QL health care literature. As table two (page 59) illustrates, only Lawton et al (2011) and Tighe et al (2011) referred to analysing across and within cases, the two main domains of QL analysis. The lack of description and reflection on practice may explain why there are fewer QL studies than may be warranted. There is a need for more methodologically orientated discussion of QL methods within health care research to encourage rigorous research practice and to allow researchers to learn from one another.

3.6 Concluding remarks

The aim of this chapter was to consider the applicability of QL methods for exploring the experience of illness and to report advantages and challenges of QLR when compared with cross-sectional, snapshot qualitative studies. Neale and Flowerdew (2003) describe QLR as a 'theoretical paradigm in itself' as it suggests a particular way of understanding the world through the temporal and social nature of experience (Neale et al., 2003). This temporal aspect is one of the key facets of QLR in addition to process and change (Holland et al., 2006). Being able to build up a nuanced understanding of what, why, and how change happens is the primary aim and main strength of QLR. Moreover, QLR encourages a flexible and iterative approach meaning that refinement can occur at all stages of the research process. According to McLeod and Thomson (2009) it is the iterative nature of QLR that makes it more than the sum of it cross-sectional parts (McLeod et al., 2009).

The challenges associated with QLR are not necessarily different from those in snapshot qualitative studies but they are exaggerated. The literature paid particular attention to the relationship between researcher and participants. The researchers involved in QLR become embedded in the process which can result in the blurring of boundaries (Saldana, 2003; Watson et al., 1991). However, with defined boundaries a trusting relationship can flourish making the research experience a satisfactory, even enjoyable, process for those involved (Watson et al., 1991; Taylor, 2009). Many of the QL researchers whose literature I have been reading spoke fondly about their participants and with a particular familiarity.

QLR is ripe for innovation and creativity within the context of each individual study. There is a fervent dialogue about QL methods and analysis in the social science literature but, by comparison, discussion in the health care literature was sparse. Overall I found that despite the increasing number of QL studies that are being conducted within the area of health care there remains little discussion about the rationale for the longitudinal design and, moreover, what additional understandings were gained from using the design. The potential benefits of a qualitative longitudinal (QL) approach for exploring the needs of people with progressive diseases have been highlighted in response to the complex, temporal changes that these patients experience (Murray et al., 2006) but, in order to encourage QLR for exploring the experiences of ill people, there needs to be a dialogue about the methodology. This PhD study can contribute to the current gap in knowledge about QLR methods and analysis and, moreover, can advance the methodology, to reflect some of the issues specific to those with serious illness.

CHAPTER FOUR
How the study was conducted

4.1 Introduction

This chapter describes how the study was conducted and ensures that the research process is made transparent. First, I recap the overall aim and objectives of the study. I then introduce the theoretical framework which has shaped this study. I include a description of the epistemology, theoretical perspective, methodology and design. I describe how I managed the ethical issues and how the participants were identified and recruited. Due to the complex chronology of the interviews in this QL study, I introduce the sample in chapter five. Next I discuss the methods of data generation and analysis that I adopted. To conclude this chapter, I describe how I engaged in a reflexive approach to data generation and analysis.

4.2 Overall aim

The aim of this study was to explore the potential of QL interviewing for examining the illness experience of patients with metastatic colorectal cancer and their carers.

4.2.1 Research questions

1. How can qualitative longitudinal interviews be best utilised to explore the illness experience?

2. What is the added value of a flexible approach with regard to the frequency and timing of longitudinal interviews?

3. Which approaches to analysis are most valuable for qualitative longitudinal interviews?

4.3 Theoretical framework

Many published research articles, particularly within medicine, focus on the methods used to generate and analyse the data, but they often neglect to report beliefs about the nature of the knowledge they produce and its meaning. Although this may be due to the stringent word limits that qualitative researchers face (Carter and Little 1997), the result is that the reader lacks the context in which to situate the findings. In the section to follow I situate my beliefs about knowledge in order to contextualise this study.

4.3.1 Ways of being – Ontological perspectives

Ontology is concerned with 'what is', and is the study of being (Crotty, 1998). According to Crotty (1998), less attention is paid to the ontological approach on the basis that ontology and epistemology are inextricably linked and often arise together (Crotty, 1998), Carter and Little (1997) argue, that in order to do research we have to make assumptions about reality, therefore a discussion about ontological standpoints is often omitted by researchers – a position they seem to advocate (Carter & Little, 2007). Although I do not want to become paralysed by a discussion about the nature of existence, a summary of the broad schools of thought is necessary in order to frame this PhD. The most commonly discussed ontological perspectives are those of realism where an objective truth can be found, and relativism where things exist as constructions of reality and there is no objective truth (Crotty, 1998). These schools of thought broadly and respectively describe the historical foundations of quantitative and qualitative research, and reflect the ongoing debate that is still be seen in the research community.

Quantitative research is, in crude terms, about numbers, probability and likelihood. It is grounded in a realist paradigm, which presupposes that objective knowledge can be sought with scientific investigation. The production of this knowledge is achieved through hypothesis generation, data collection using positivist methods such as survey research, and statistical analysis which will either support or reject the hypothesis. However, such designs fail to consider the social, cultural and political contexts in which

knowledge can be understood (Westerman et al., 2008; Carr & Higginson, 2001; Cox, 2003). Herein lies the premise of qualitative research methods; they belong to a relativist paradigm and can access areas which are contextually embedded in experience. Within this relativist paradigm there exists a spectrum of perspectives and methods from a more prescriptive, objective standpoint to a subjective, relativist standpoint. The illness experience cannot be quantified using numbers, probability or likelihood, rather it is characterised by subjective feelings which can be best explored using a qualitative approach.

4.3.2 Ways of knowing - Epistemological and theoretical perspectives

4.3.2.1 Epistemology

Epistemology is the descriptive term used to define the nature of knowledge, and what it means to know (Crotty 1998). The epistemological perspective defines and justifies the theoretical perspective, methodology, and the methods used in research – this reflects a methodologically pure top down approach which is illustrated in figure three (page 71) (Crotty, 1998). However a bottom up approach also applies, where the epistemology is informed by the most appropriate methods to answer the specific research question (Carter and Little 2007). I believe this latter scenario is more common in the real world, particularly in today's fragile financial climate, when money for research is scarce and thus has to be used resourcefully. Within the literary descriptions of epistemological perspectives, there remains a great deal of debate on the dominant schools of thought. However, Crotty (1998) described them broadly as objectivism, constructionism and subjectivism (Crotty, 1998).

The researcher is integral to the generation of data and meaning in qualitative research. The epistemological perspective influences the relationship between the researcher and; the participant, the quality of the findings, the audience and what is known (Carter et al.,

2007; Denzin & Lincoln, 2000). Moreover the epistemology justifies the findings and meanings of the research (Carter et al., 2007). So, how do I locate myself in this study? How do I view the social world? My undergraduate degree was in nursing studies, which Carter and Little (2007) suggest may influence my perspective (Carter et al., 2007). Contemporary nursing studies is now an academic discipline (in contrast to the practical discipline that it was historically) which is informed by both realist (in its proximity to medicine) and relativist (in its proximity to social sciences) paradigms. My training in nursing instilled in me the importance of listening and engaging with people, and hearing their stories. Therefore it is no coincidence that I am invested in qualitative research and narrative methods, the latter of which will be discussed in more detail later in this chapter.

The aim of this PhD is to explore the potential of QLR for understanding accounts of the illness experience. An objectivist epistemology which seeks to uncover the truth would be an inappropriate framework to explore the subjective experience of illness. I anticipate that common themes, not truths will emerge. What about a subjectivist approach? According to Crotty (1998), this is an approach which is often confused with constructionist approaches and is not concerned with the object, but instead the view of the object (e.g. illness experience), from the subject (e.g. participant). In other words, subjectivists are solely concerned with the meanings of the external world as described by the participant which, for the purpose of this study, fails to reflect the context in which individuals live their lives and are experiencing illness.

Having rejected objectivist and subjectivist epistemologies my philosophical journey continues by considering the following; the importance of context; how knowledge and meanings are individually constructed in the context of social phenomena; how the participant lives within their relationships and finally how I interact with the participant will influence the research. Thus, I need an approach which is not at either extreme of the epistemic spectrum. A constructionist epistemology proposes that there is no

objective truth to discover from reality, and that truth comes into existence when individuals interact with the world. Crotty (1998) defined constructionism as follows,

> "it is the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context" (Crotty 1998: 42)

I believe that the knowledge and meanings which are generated from this study will be the result of the interaction between myself, and the participants, so what theoretical perspective best reflects this constructionist approach?

4.3.2.2 Theoretical perspectives

Within a constructionist epistemology there are a number of theoretical perspectives which give context to the methodology of the research, and provided the reader with a description of the view of the human world (Crotty 1998). Like the epistemological standpoint which underlies research, the theoretical perspective is often discipline dependent. Indeed, it was highlighted in the introduction to chapter three (page 40), QLR is considered a theoretical paradigm in its own right, as it implies that experience is understood over time (Neale et al., 2003). If QLR is understood over time, then interpretation and re-interpretation is implicit to how knowledge is produced. With this in mind hermeneutics, which is often adopted in health care research and is constructionist in epistemology, fits well with the QLR paradigm in that the focus is on the interpretation and re-interpretation of texts and language. Hermeneutics has been used as a way of understanding human action, events and situations through language (Crotty 1998). Modern hermeneutics is commonly used in nursing research, and as a result, the main distinctions between Husserlian transcendental phenomenology and (modern) Heideggarian/Gadamerian hermeneutics have been described in the nursing literature (Koch, 1995; Lopez & Willis, 2004).

Thus far I have concluded that a qualitative approach will be most appropriate to explore the illness experience, and my belief is that knowledge is a joint construction between the researcher and the researched. A hermeneutic approach is consistent with a

constructionist epistemology and the QLR paradigm, as it is concerned with language, and interpretation and re-interpretation. Therefore, this study requires a methodology where the researcher is integral to the generation of data and process of analysis and is concerned with language.

4.3.3 Ways of doing - Methodology

The methodological approach informs and justifies the methods that the study will adopt to generate and analyse the data and should reflect the appropriate theoretical perspective. The range of methodological approaches that are commonly used include grounded theory; phenomenological research; action research; discourse analysis, ethnography and case study research (Crotty 1998). The methodology should be concurrent with the outcome of the research and according to Carter and Little (2007) should be thoughtful and theoretically and historically situated. I have adopted narrative inquiry as the methodology for this PhD. The production of narratives is a common way of using language and making meaning. Storytelling is an inherently social act which is framed in a constructionist epistemology - stories are told by someone, for someone (Elliott, 2005). Indeed, Lopez and Wills (2004) suggest that interpreting the meaning of phenomena in the context of illness is only possible through the analysis of narratives (Lopez et al., 2004)

4.3.3.1 Narrative inquiry

The art of narrative inquiry is a long-standing tradition, which is grounded in a number of disciplines including linguistics, psychology, the social sciences and more recently health care studies. The discipline has evolved, and now traditional analyses have been devised and modified to reveal a diverse range of techniques that can be adopted. Despite this diversity, there remains a lack of consensus on the definition of a narrative, and controversy surrounding the key features still exists. Elliot (2005) describes the main features of narratives as; chronological and represent a sequence of events; they are

meaningful; and they are inherently social and produced for a particular audience (Elliott, 2005).

The study of illness narratives has gained popularity over recent decades, as chapter two (see 2.7.2.2, page 33) illustrated. Narratives are commonplace within medicine, and are told by those suffering from illness and those caring for the suffering, making it an ideal methodology for exploring the experience of illness. When an ill person is asked about their medical history they are telling a story, often a well rehearsed story if they have had a complicated illness career (Frank, 1995). There may be stories about relationships (doctor/patient; patient/carer; multidisciplinary team); stories about the cultural aspects of health care (service provision); stories about the physical experience of illness; stories about the experience of dying. Given the diversity of the contexts in which illness narratives are found, it is not surprising that the study of illness narratives is gaining popularity.

Figure three (page 71) summarises the theoretical framework of this PhD. Much of this section has been informed by Michael Crotty's (1998) text entitled, 'The foundations of social research: meaning and perspective in the research process' and the diagram to follow has been adapted from his useful flowcharts on pages four to six of the book.
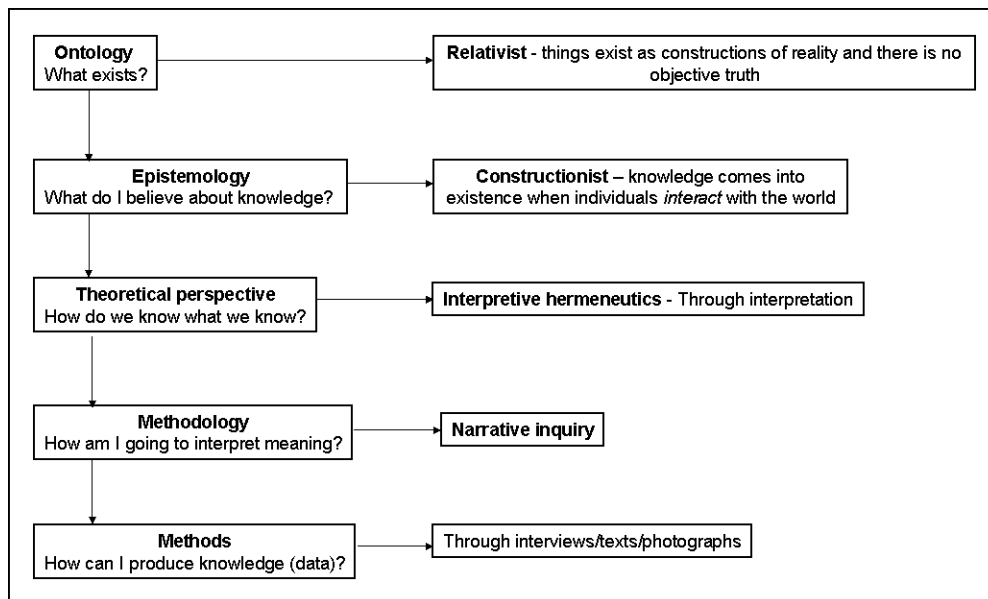
Figure 3. Summary of theoretical framework. Adapted from Crotty (1998) pages 4-6

4.4 Design

As the research questions were refined throughout the course of the first year of study, the design evolved in parallel. Data were generated using face to face, semi-structured interviews and phone calls at regular intervals over the course of 12 months. The methods of data generation are discussed later in this chapter (page 80).

4.4.1 Flexible approach to data generation

Previous studies using a QL interview approach have tended to adopt empirically determined intervals between interviews, where the time span is led by the research agenda (Corden et al., 2007a). With this issue in mind, further understanding the optimum time to interview and how these interviews should be initiated, would be of use to the wider community. Therefore, this study was designed to include two groups of participants. Details of the participants in each group and the chronology of the interviews and telephone calls will be provided in chapter five.

Group 1 - Routine interval group, herein entitled the six monthly group, where interviews were carried out at regular intervals of six months to a maximum of three over one year. I had initially planned to conduct the interviews at four monthly intervals but, after discussion with the health professionals at the recruiting centre, it was changed to six monthly intervals, as the participants seemed to be reasonable well when I first met them. I discuss this further in chapter nine.

Group 2 - Flexible interval group where there was an interview at baseline followed by monthly phone calls which tracked changes in the participants' circumstances. Participants in this group were also interviewed a maximum a three times over the course of the year. If an early interview was not indicated during a monthly telephone call the participant a face to face interview was conducted at month six.

4.4.2 Multi-perspective interviewing

Where possible, the study adopted a multi-perspective approach, where family carers - described as someone sharing the experience with the participant - were interviewed alongside the individual with cancer. During the thesis I refer to the interview dyad, meaning the patient and the carer. The practice of multi-perspective interviewing is detailed in section 4.7.3.7 of this chapter. As was reported in a paper which I co-authored during the course of this PhD which can be found in appendix two (page 292), this technique can facilitate the generation of contextualised and rich data (Kendall et al., 2009). Details of the informal carers who agreed to participate are provided in chapter five.

4.5 Ethical dimensions of research

4.5.1 Professional ethics - Ethical review process

Ethical approval for this study was granted by the local Research Ethics Committee (REC) in September 2008, and can be found in appendix three (page 297).

Simultaneously, Research and Development approval from the local National Health Service (NHS) board was also required and was granted. This incorporated an honorary NHS contract for my work in the field. This proved useful when I first visited the clinical areas as I found it legitimised my presence. I found the ethical review process massively beneficial, as it offered an opportunity to gain clarity on the process of carrying out the research. The process itself also encouraged early networking with those I was collaborating with at the recruiting centre. Early contact with the clinical nurse specialists in the first instance, and subsequently the consultant oncologists meant that queries were resolved early in the research process. At a much more rudimentary level, this early contact gave the staff a chance to meet me before I was to be immersed into the busy clinic, and introduced to patients and their families.

Having submitted the REC application the committee asked me to amend two main aspects of the study. Firstly, the committee asked me to ensure that the consent form stipulated that the interview transcripts, and relative data would be stored securely at the University of Edinburgh for five years. Secondly, they asked that before calling the homes of the participants I confirmed that they had not passed away in the interim. This proved to be a very useful point that I had not considered, which highlights the value of the ethics process as a whole. This will be discussed further chapter eight (page 232).

4.5.1.1 How data were handled

As required by the ethical committee, all data were handled in accordance with the principles of confidentiality, from the outset of this study. Only the immediate research team, consisting of myself and two supervisors, have access to the data which are stored securely at the University of Edinburgh.

The data for this study comprised of demographic information, field notes, audio-recordings and interview transcripts. At all times security measures were taken in place as stipulated by the University of Edinburgh and the REC. The data will be stored for a

period of five years before being destroyed. Similar security is in place for the audio-recordings which are stored on a locked computer. Any audio-recordings on my digital recorder were deleted at the earliest opportunity. An Excel file that holds the demographic information about each participant is electronically locked and can only be accessed by the researcher. If at any time this information was required for the purpose of a research team meeting, the names and addresses were deleted from the printouts. Each participant was assigned a folder that was stored in a lockable filing cabinet at the University of Edinburgh. Paperwork, such as signed consent forms, were stored in this cabinet and will be archived.

4.5.2 Research ethics - Naming and anonymity

Following recruitment into the study patients and carers alike were given a unique identification number. However, in this thesis each participant has been given a pseudonym. The politics of naming participants in qualitative research, with either their own names, or pseudonyms was discussed in a recent paper by Guenther (2009). The author argues that qualitative researchers regularly fail to discuss their reasons for naming (or not naming) participants in research studies. She argued that it is an important decision which should be justified in the same way that other methodological justifications required of us (Guenther, 2009). Maintaining the confidentiality of participants is one of the biggest concerns for researchers, and, although the ethical approval process alerts us at the earliest opportunity to potential areas of concern, it is an ongoing process. Guenther (2009) argued that a balance must be sought, as the use of pseudonyms may encourage recklessness when presenting potentially identifiable data. However, not using them may encourage researchers to be over cautious putting them at risk of making false claims about the data which are fundamentally detrimental to the research. Tilley and Woodthorpe (2001) also highlighted that the issue of anonymity is a complex one, that may conflict with the research agenda, dissemination and knowledge transfer (Tilley & Woodthorpe, 2011).

The narrative approach to this PhD intends to give a voice to those who are often unheard or silenced. As a result I felt uncomfortable when I was originally referring to the participants by a number. As a health care researcher, I am bound by the rules of the REC, and must operate within the parameters set by them. Consequently, it would be unfeasible to use participants' own names but by assigning each a pseudonym, I can give a voice to the participants, and improve the cohesiveness of the research story (Guenther, 2009). Moreover there exists the issue of internal confidentiality, where the participants in the study may be identifiable to the recruiting institution. Recruitment for this study would have been impossible without the support of the consultant oncologists and specialist nurses who helped me identify potential participants. However, this means that these health professionals know who was recruited into the study. Thus, careful attention has been paid to how much demographic information is presented to contextualise the study. The quotes that I have given reflect this, and it will become evident that there are times when certain names, or aspects of the participants' lifestyle have been omitted.

4.6 Participation

4.6.1 Sampling

The two most frequently adopted techniques for sampling in qualitative research are purposive and theoretical methods. Some propose that theoretical sampling falls within a broader category of purposeful methods and is generally used in studies with a grounded theory methodology (Coyne, 1997). According to Silverman (2000), theoretical sampling is an iterative technique where participants are deliberately sampled as themes are developed thus encouraging the researcher to seek a wide ranging sample to reflect emerging themes (Silverman, 2000). Whilst theoretical sampling is a valuable method for a grounded theory study, the narrative methodology of this PhD study means that a purposive sampling method was most appropriate. In this way the sample was

recruited to reflect the particular phenomenon I wished to investigate. As Silverman (2000) suggested,

> "Purposiveful sampling allows the researchers to choose a case because it illustrates the feature in which we are interested." (Silverman 2000: 104)

The section to follow highlights how the participants were identified, approached and recruited. The sample was purposively recruited to reflect a range in age, gender, time since the diagnosis of metastatic disease and the presence of an informal carer - who was defined as a friend or family member who was involved with the patient at home. These were classed as the main variables, but further pragmatic decisions were made as to the prognosis of the patient; did the consultant oncologist think them likely to survive to participate in at least two interviews?   I purposively recruited to ensure that both the six monthly interval group and flexible interval group had similar participant demographics to facilitate comparison during the analysis phase of the study.   Where possible, I matched the participants in each group on the basis of gender, age and the presence of an informal carer.

4.6.2 Identification

This study was carried out in Scotland. The recruiting centre has approximately 26,000 patients under their care, and of these 2400 have colorectal cancer.   In 2008, approximately 4500 new patients were referred to the centre, of whom 550 had colorectal cancer (personal communication with recruiting centre).

I sought to recruit a total of 16 participants with metastatic colorectal cancer and an informal carer if the participant nominated one. The longitudinal nature of this study meant that there was the potential for the total number of interviews to equal 96 individual interviews (16 patients x 3 interviews + 16 carers x 3 interviews), in addition to field notes from monthly telephone calls with the eight participants in the flexible interview group. This ambitious total was calculated before attrition, and was based on every patient nominating a carer to be interviewed separately - although unlikely it was a

necessary consideration. Therefore, after consulting with the research team, and other experienced researchers, a pragmatic decision was made that a total of 16 participants and their carers would be sufficient to answer the methodologically orientated research questions yet still allow for possible attrition and loss to follow-up over the course of the study. The number would also enable me to retain a close relationship with the participants as Crouch and McKenzie (2006) suggested (Crouch & McKenzie, 2006).

Crouch and McKenzie recruited a small sample of seven women post-mastectomy in order to understand each experience and subsequently connect these experiences with existing concepts (Crouch & McKenzie, 2000). Likewise, Yates (2003) argues for a small sample of the basis of reflexivity and relationship. Yates and her colleague Julie McLeod recruited 26 participants to QLR over a period of eight years (Yates, 2003). They report that in the context of educational studies this is a small number, but in order to fully engage with the data they wanted to carry out the interviews and analysis themselves hence the small number of participants (Yates, 2003). My decision to recruit 16 participants; a small number for a study within a discipline which is dominated by quantitative research, finds support in the work of Crouch and McKenzie (2000) and Yates (2003).

4.6.2.1 Inclusion and exclusion criteria

Silverman (2000) emphasised the importance of researchers adopting critical inclusion and exclusion criteria to ensure the rigour of the research. The inclusion criteria for this study were:

- 16 patients with colorectal cancer recruited to reflect a range in age and sex.
- All patients had been given a diagnosis of metastatic colorectal cancer within 18 months of the date of recruitment.
- The location of the metastases was not specified, only that the primary tumour was colorectal in origin.

- If present and willing to participate, informal carers were nominated by the patient in keeping with a patient-centred approach.

- Those with moderate to severe cognitive dysfunction (as diagnosed by a physician) were excluded from the study on the basis that the longitudinal nature of the study may result in upset to the participant over the course of the study.

- Those with operable liver metastases or those who had already undergone liver surgery were excluded from the study. After consultation with colorectal oncology specialists I was informed that, after the liver metastases had been removed via surgery, patients are deemed free of metastases.

4.6.3 Recruitment

Each week I attended the colorectal oncology outpatient clinic at the recruiting centre. This was an extremely busy clinic where four consultant oncologists and two junior doctors met with approximately 50 patients in four hours. Recruitment was significantly aided by the help of the colorectal nurse specialists at the recruiting centre, to whom I am indebted. Recruitment commenced in October 2008, and the last participant was recruited in July 2009[12]. To encourage diversity within the sample, a table providing the demographics of each newly recruited participant was updated every week which meant new participants could be recruited accordingly.

The clinical nurse specialists would advise me about potential participants who were attending the clinic that day. I would then personally approach the consultant oncologist and ask if they would be willing to introduce the study, and latterly me to the patient. When the potential participant had returned to the reception area, often awaiting blood tests, I would take the opportunity to introduce myself and tell them a little about the

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[12] Although recruitment was delayed between October 2008 and Jan 2009, it is evident that recruitment was a lengthy process and took longer than any of us had anticipated, including those I was working with at the recruiting centre. I will discuss this further in chapter nine.

study. I kept the information I divulged at this stage to a minimum, as often people had been waiting a considerable amount of time before the appointment and for many it was an anxious time and a long morning. Nevertheless, people were generally keen to speak to me and when this was the case I told them my name, that I was a PhD student and that the purpose of the study was to find out a bit more about the experience of having colorectal cancer and to improve the way we carry out research of this nature in the future.

I felt it necessary to be upfront about the methods aspect of the study, in addition to the fact that the study was being carried out as part of an educational degree. I explained that their involvement would entail up to three interviews over the course of a year, and for the flexible interval group that it would additionally involve a telephone chat every month. Where a carer or significant other was in attendance at the clinic appointment, I encouraged them to be present at the initial discussion, as ideally the study would also involve their participation. After explaining the purpose of the study I issued each potential participant and carer with a participant information sheet (PIS), and advised them that I would telephone four days later to discuss any queries and assess their willingness to participate. This PIS can be found in appendix four (page 299). The REC advise that a minimum of 48 hours is appropriate for participants to read the information sheet, and have thought about what participating in the study would involve for them and the impact it may have. I felt that four days was a good balance between pressuring people by calling too soon and leaving it too long that people had forgotten. As promised, I called four days later and if willing, arranged a time to meet for the interview. Interviews were ideally scheduled to occur within two weeks of us first meeting at the clinic to ensure continuity.

4.6.3.1 Those who declined to participate

A total of seven individuals declined to participate in the research; namely four women and three men, ranging in age from 51 to 67 years. Of the men, one declined when

approached by the consultant as he was struggling to cope with the treatment regimen. Two of the women declined participation when approached by the consultant for personal reasons. The remaining four declined after reading the PIS at home. Within this group, one man described that he was just starting to feel well again after his chemotherapy treatment, and was returning to work. One woman had complicated family problems at the time. Both of these individuals expressed that participating may have been beneficial had it been at another time. The remaining two individuals did not want to talk about their illness and therefore declined participation. I thanked all these individuals for considering the study and wished them well for the future. This group of non-participators show similar demographic characteristics, in terms of age and the site of the cancer to the final 16 which is encouraging for the rigour of the study.

The sample of patients and carers who kindly gave up their time to participate in this study will be described in chapter five of this thesis, as will the chronology of the interviews.

4.7 Data generation

4.7.1 The practice of qualitative interviewing

The methods applied to generate the data were determined by the underlying epistemology and the research questions. For the most part qualitative research uses interviewing techniques, focus groups and ethnographic methods to generate data. Interviewing methods comprise the most commonly used research tool for generating data in qualitative research and are generally used in studies which are grounded in phenomenological, hermeneutic and post-modern epistemologies (Kvale 1996). Through the medium of language - vocal and body - individuals can describe their experiences and what illness means to them. Mishler (1986) suggested that positivist quantitative survey methods are unable to capture the subjective experience, as standard questioning in structured interviews generates standard responses (Mishler, 1986). In

the context of this PhD study, interviewing techniques seem the most socially inclusive method when generating data from a potentially diverse sample. Other methods that are used to elicit narratives, such as visual or diary techniques are labour intensive which may make them unsuitable for potentially unwell participants. However, conversation is the most common form of communication in everyday life and interviews can be viewed as an extension of the norm (Mishler, 1986). Mishler (1986) argued that in-depth/semi-structured interviewing facilitates the exploration of the participants' social, cultural and political understandings (Mishler, 1986). On the basis of Mishler's (1986) argument, interviewing is an appropriate method for this study, which seeks to explore the illness experience.

Interviewing as a research tool is often taken for granted and mistakenly considered a simple alternative to quantitative methods of generating data (Kvale, 1996; Fontana & Frey, 2005). As a result of this, the quality of interview studies often comes under scrutiny (Roulston, 2010). However, when carried out in a reflexive manner interviews can bestow a powerful and unique medium for understanding experience and social phenomena. Interviews not only portray specific understandings of the social world, but also encourage participants to frame their own understandings of the social world through dialogue (Roulston, 2010). Interviewing in the context of this PhD refers to open, in-depth and semi-structured techniques as opposed to structured, closed questioning.

According to Kvale (1996), research interviews should strive to "renew, broaden and enrich the conceptions of knowledge." (Kvale, 1996: 10). He argued that in order to action this, researchers need to be explicit about the methodological and theoretical frameworks that inform the research. Much of the criticism towards interviewing techniques in the literature, stems from researchers' lack of transparency with regard to the methods of data generation. Hopf (2004) concluded that the problems which arise from interview methods are the result of suboptimal training, rather than a lack of

appreciation for theoretical underpinnings. Thereby Hopf (2004) proposed that the main problems are due to communication, for example, the researcher's ability to dominate the interview. Lack of patience and inflexibility when using an interview or topic guide can amplify the problem with communication (Hopf, 2004).

According to Kvale (1996), interviews should be an inter-change of ideas, meaning the researcher is as engaged in the interview process, as the participant, which highlights the importance of reflexivity on the part of the researcher. Insights and contemplation on the research relationship is of vital importance, as this is the key tenet which distinguishes everyday conversation from the research interview (Mishler, 1986). The researcher is the key to this end, and through critical attention to participants' responses, the researcher can facilitate the dynamic flow of the interview. The inter-change of ideas - seeking knowledge, not truth - facilitates an active engagement within the dialogic interview, and therein lies its strength (Kvale, 1996).

4.7.1.1 The narrative interview

Narrative methods are applied to both generating and analysing data therefore the conduct of the interview needs to elicit narratives. According to Mishler (1986), the narrative interview is generally considered a form of qualitative, in-depth interview, which attempts to elicit stories from the participants – where the participant is a narrator, who gives meaning to the stories as they are told (Mishler, 1986). The main aim is to encourage the production of narratives and thus the researcher has an important role to play as questioner, listener and co-participant (Mishler, 1986; Bauer, 1996). Mishler (1986) advocated that the researcher let the participant continue without interruption when they are responding to the interviewer, which is what I sought to do. Moreover, I was influenced by the biographical method of interviewing which has been cited as a method of encouraging participants to elicit stories (Hollway & Jefferson, 1997). Details of how I approached interviewing the participants in this PhD study will follow.

4.7.2 Development of the interview schedules

A comprehensive interview guide was developed for the first round of interviews which can be found in appendix five (page 302). This initial interview guide was developed according to the literature concerning the experience of illness. Consultation with the research team finalised the topic guide before it was submitted and approved by the ethics committee. The questions fell broadly into the following themes; physical, psychological, social and spiritual needs and experiences. To contextualise these four domains, I was also concerned with the participants' direct experiences of care, what the individuals perceived their needs to be and their understanding and experiences of communication during the time of their diagnosis and illness.

This topic guide comprised of open and closed questions capable of stimulating thought and further questioning during the interview. The main purpose of this guide was to provide a structure to the interview, but it also proved useful on the few occasions when I felt the interview had become stagnant. Although some of the questions were relatively prescriptive in nature, I strived to be true to the narrative methodology and to ensure a conversational approach was adopted to elicit stories. Equal emphasis was given to generating the data, and to building a rapport and relationship with the participants.

4.7.2.1 Evolution of the interview schedule for subsequent interviews

The topic guide in appendix five (page 302) was only used in the first interview with each participant. The second and third interviews were tailored to each participant and were designed to expand upon the topics and themes that were generated in the previous interview, thereby ensuring an iterative process. This technique became easier over time as the participants and I got to know one another. I carried with me a question guide, which had been specifically tailored to each participant and to each subsequent interview. Each question guide comprised of four or five general questions which resulted from the analysis of the previous interview. For example, existential issues and

seeking meaning in his life were themes from my first interview with Duncan, so the topic guide for our second interview consisted of the following questions:

- So, what's been happening in the last six months?
- Would you describe yourself as a spiritual person?
- What does spirituality mean to you?
- What do you think has changed over the last six months?
- Have you changed your mind about McMillan support?
- What keeps you going? What helps you cope?

By using this technique I was consistently encouraged to reflect upon the participants' dynamic and changing experience.

4.7.3 Conduct of the interviews

4.7.3.1 Procedure of consent

The patient and carer consent forms used in this study can be found in appendices six (page 303) and seven (page 304) respectively. Note, that these were the consent forms for participants in the flexible group which included an extra clause regarding telephone interviews. For the interviews that were carried out in participants' homes, I would arrive as planned and as I entered the house I would remind them of my name. Similarly, when the interview was carried out at the hospital (which was the case for two participants), I met the participant in the waiting room; often after a clinic appointment. When everyone was comfortable I first verbally described the consent form, highlighting that if they agreed there would be three interviews (and phone calls for the flexible group) over the course of the year, but that they could withdraw from the study at any point should they wish. I assured participants that they would be unidentifiable to anyone but me and, that although the research team may see the interview transcripts, their identity would remain anonymous. If participants acknowledged that they were happy to proceed, I notified them that I would inform their GP and that the interview transcripts, and any notes I made would be stored securely at the University of

Edinburgh for a period of five years. At that point I would ask participants if they had further questions about any aspect of the study and would they be amenable to having the interviews recorded. If they were happy to continue I would ask them to sign the consent form and the interview commenced. The consenting procedure for participants and carers was the same.

The REC agreed that I did not have to obtain written consent for the later interviews. Rather, by agreeing to participate in second or third interviews at the time of the phone call consent was implicit. I worried that asking participants for written consent again might have hindered the rapport and conversational style that characterised the later interviews. Therefore I was pleased that the ethics committee were in agreement. However, when we met face to face the participants were reminded that they could withdraw from the study at any time, even during the interview if they wished. As a number of the participants experienced episodes of critical illness, there was a chance that they may have been admitted to the hospital, a hospice or had died in the interval between the interviews or telephone calls. It is for this reason, the ethics committee asked me to ensure that I confirmed the whereabouts and status of the participant before calling their home. Unfortunately, this proved challenging due to poor communication between primary care, hospice services and secondary care. I share these experiences, and reflect on the ethical dilemmas I faced pertaining to this in chapter eight.

4.7.3.2 The first interview

I commenced each interview by asking the participants to tell me what had happened to them. This encouraged people to tell me their own story, in their own words, and to start their story where they felt it most appropriate. Did they want to start their story from when they first started experiencing symptoms of cancer? Did they want to start with their experiences as a child? Thus, by asking an open ended question I gave each participant the opportunity to determine where their story began. In addition to hearing participants' own stories in their own words I was also able to collect vital contextual

information to supplement the narratives (Ritchie & Lewis, 2003). When each participant's story came to a natural end I sought to follow up on loose ends in the narrative; many of which appeared as a topic area in the interview guide. This technique meant I was able to establish a chronology of their experiences.

4.7.3.3 Subsequent interviews

In the case of the second and third interviews, I similarly commenced each interview by asking participants to tell me what had happened since the previous interview. They often asked to be reminded of when that was, and what was going on at the time of the last interview, which was useful for ensuring the temporal element to the study. This also helped me to build on the rapport which had been developed at the previous interview, as it showed participants that I had been listening to them. Where possible I made an effort to remember the names of their children, sibling, pets etc. with the same idea in mind. After listening and responding to the participant's opening narrative I asked them to expand on the themes which had arisen from the previous interview. In this way I was ensuring an iterative approach rather than a repeat cross-section of data (Smith, 2003).

4.7.3.4 Closing the final interview

The final interviews with those who survived until the end of the study, were often an emotional affair as together we had shared intimate conversations, laughter and tears. Having said this, I was aware of the importance of sensitively closing the interviews, and ensuring that the participants knew that I would not be returning. For some, the end of the interviews signified more than just the end of their participation in the study, because several participants passed away not long after the study had ended. In this case, the farewell felt final – for both of us.

4.7.3.5 Handling sensitive issues

The conversational style of narrative interviewing that I encouraged was consistent throughout all the interviews, and it created a comfortable platform for people to share their experiences and discuss sensitive issues. There were occasions during some of the interviews when participants became visibly upset, and I gave them the option to end the interview or pause for a while. All were determined to continue so I compassionately supported them to finish their story. My experience in nursing proved beneficial when these distressing situations arose, as I felt prepared to deal with the situation tactfully and with empathy. I shared these experiences during my formal supervision meetings as a way of de-briefing. I also felt well supported by the Primary Palliative Care Research Group who has experience of similar studies.

4.7.3.6 Telephone interviews

Monthly telephone calls were conducted with the participants in the flexible interval group, which enabled me to maintain the relationship we had developed, and to keep up with changes in the participants' circumstances. It was decided early on in the study that such phone calls would not be recorded, but instead I would write detailed field notes regarding the interaction. The structure of these field notes will be discussed later in this chapter. I wanted to encourage more of a conversational style of interviewing for the monthly calls, and was concerned that by recording them and reminding participants every time that they were being recorded, would stifle the dialogue. There were pragmatic limitations to the telephone calls, and sometimes I had difficulty getting hold of people, such that not all telephone interviews were conducted a month after the previous.

Telephone conversations are a well used mode of social interaction, which, in modern Britain are not socially or age exclusive (Holt 2010). As Holt (2010) suggested, their success in terms of research output, is as much to do with the telephone skill and comfort of the participant as much as the interviewing skill of the researcher (Holt

2010). For example, I found that stereotypically, the male participants in this study were not as forthcoming on the telephone as the female participants.

The methodological concerns that are raised by Sturges and Hanrahan (2004), and later Holt (2010), during their commentaries regarding telephone interviewing, are partly overcome in this study due to the combined use of face to face and telephone interviews. The two main criticisms of telephone interviewing are that there are no visual cues from which to work (Sturges & Hanrahan, 2004) and that it is impossible to rely on contextual, ethnographic data that the researcher would normally pick up from a face to face interview (Holt, 2010). I was able to overcome the latter criticism, and use this information to inform the face to face interviews, because the telephone interviews in this research project were supplementary. Furthermore I would share the view of Sturges and Hanrahan (2004) who concluded that the success of telephone interviewing in their study was partly due to the fact that they carried out face to face recruitment.

The telephone conversations that the participants and I shared ranged in time from one minute to approximately 40 minutes. Before every call I would read the detailed field notes that I had documented after the previous call or interview and decide on general topics to cover. There were often particular events that I had to follow up, such as the outcome of clinic appointments, scans and treatment.

4.7.3.7 The multi-perspective approach and joint interviewing

Where possible I interviewed informal carers, in addition to the patients to gain multi-perspectives of the patient's experience of illness. At the time of first contact with potential participants, I told them about the aim of interviewing a carer if there was such a person around. Morris (2001) highlighted the difficulty in using the term 'carer' in her study. I identified with this and realised at the time of recruitment that I would have to qualify verbally to potential participants what I meant by the term carer. Like Morris (2001), I described the carer as someone who was sharing the cancer journey with the

participant (Morris 2001). I also had to stress that this did not necessarily be a husband or wife - which was often the assumption - but could in fact be a child, sibling or even friend.

Patients often attended clinic appointments with their informal carer, so I took the opportunity to speak to them at that time if they were amenable. If the carers were present I gave them a PIS (appendix four, page 299) so they could learn more about the study, and what their potential role may entail. Likewise, if the informal carer did not want to be involved, I still gave them a PIS so they knew what the patient was becoming involved with. I approached the joint interviews in the same fashion as individual ones with the aim of facilitating the production of a narrative; sometimes in the case of the joint interview - a joint narrative. I used the same topic guide as the individual interviews yet I did make an effort to ask carers about their experiences of the patient's care throughout the interview.

In chapter five I provide a breakdown of the interviews at each time point, when an informal carer was recruited, and if they preferred to be interviewed jointly with the patient. Only one patient/carer (brother/sister) dyad opted to be interviewed individually. Moreover I did not want to cause undue stress by stipulating that they had to be interviewed without their loved one. Indeed, in some cases, the patients did not want a carer to be involved and preferred to be interviewed alone and sometimes without the carers' knowledge that it was happening.

4.7.3.8 Bereavement interviewing

Bereavement interviews were carried out with carers after the death of their loved one. The purpose of these interviews was to establish the circumstances surrounding the patient's death, and the carer's experience. When I heard that the participant had died (usually from the nurse specialists at the recruiting centre), I sent the carer a sympathy card, and followed up with a phone call approximately one month later

Naturally these telephone calls and interviews had to be handled sensitively, but due to the relationship which had evolved over the course of the study, I felt better prepared to achieve this. The interviews were often upsetting for both the carers and myself, so I generally spent some time after the recorder had been turned off chatting to the carers, in order to de-brief and to ensure their emotional wellbeing before I said goodbye.

4.7.4 Field notes

Following every interaction I had with participants I wrote detailed field notes. These interactions included interviews, telephone calls and chance meetings, which were usually at the clinic. As I was in attendance at the outpatient clinic every week to recruit new participants, I would often meet those who had already been recruited. All field notes were written within 24 hours of the interaction when it was fresh in my mind. Following each face-to-face interview I would write an interview summary, where I would summarise what was said in my own words, whilst reflecting on what I saw as the significant topics of discussion. I would also comment on the physical condition of the participants, and what seemed to have changed since our previous meeting. In addition to reflections on the participant's physical condition, and my immediate feelings about the content of the interview, I documented:

- Observational notes about the surroundings in which the interaction had occurred - what I could see, hear, smell etc.
- Methodological notes, where I reflected specifically on longitudinal aspect of the study
- Theoretical notes, where I documented any hunches about the interview
- Personal notes, where I offered a critique of my conduct during the interaction and my emotional response (Richardson, 2000).

Personal notes were often laboured by my thoughts and feelings about my encounter with the participant, which proved a necessary way for *me* to de-brief. This same structure was used to document my thoughts after every telephone call.

Richardson's (2000) structure proved a useful template for me to organise my thoughts. The broad nature of the template encouraged me to be detailed in my reflections, whilst allowing a particular focus on the methodological aspects of data collection – a necessary feature given the methodological topic that I was investigating.

4.8 Analytical approach

In order to explore the analytical potential and to inform the QL methodology, every transcript was subjected to two types of qualitative analysis. The first was a narrative analysis which was developed by Brown and Gilligan (1992), which is rarely used in health care research despite its potential (Pinto, 2004). The second was a thematic analysis using the principles of grounded theory (Charmaz, 2006) which is often used by health care researchers. To ensure a coherent description of how the overall analysis was conducted I elaborate on the Voice Centered Relational Method (VCRM) by Brown and Gilligan (1992), and how it was conducted both cross-sectionally and longitudinally. Likewise, I discuss how I conducted the thematic analysis.

4.8.1 Transcribing

All interviews were transcribed verbatim and colloquialisms were kept in the written transcript for authenticity. Any utterances made by myself (e.g. uhuh, yes, okay, right, etc.) were kept in the transcript, but were put in brackets within the participant's monologue to maintain the cohesiveness of the participant's overall narrative. This will be evident in the quotes throughout this thesis. All the interviews at T1, and several from T2, were transcribed by myself. The remainder were transcribed by a paid transcriber, but were checked against the recordings, first by the transcriber and then by me to ensure their accuracy.

I shared an office with the transcriber, which meant that regular, informal de-briefing sessions were held when we safely transferred the audio-recordings for transcription.

These informal sessions were necessary, as the interviews could be upsetting to listen to, and I saw that I had an ethical obligation to ensure the emotional wellbeing of my transcriber (Kendall et al., 2007; Harris et al., 2008). Where possible, I tried to have the written transcript prior to each subsequent interview, but due to time constraints, and the flexible approach to interviewing, this was not always possible. If I did not have the written transcript to hand prior to subsequent interviews, I listened to the full audio-recording of the interview and whilst listening, carried out the VCRM narrative analysis. In so doing I ensured the iterative approach that was necessary for this longitudinal study.

4.8.2 The use of Computer Analysis Qualitative Data Analysis Software (CAQDAS)

In order to manage the large volume of data that were generated in this study I used QSR NVivo Version 7 (QSR International Policy Ltd, 2006) for the thematic analysis. A new NVivo project was commenced at each of the three time points and the coding framework from the previous analysis was uploaded and adapted for each new thematic analysis. I did not use NVivo for the narrative analysis, although I did attempt it when I first commenced the narrative analysis. I found that I was fragmenting the participants' stories which contradicted the very essence of the VCRM. However, in order to gain an insight into the participants' experiences at each time point I used NVivo to help me collate the themes from both the narrative and thematic summaries which I wrote after each time point analysis. Although I was using NVivo more for its organisational capabilities, than its analytical ones at this point, I unexpectedly found that it encouraged me to think about the hierarchy of the themes that had developed to describe the participants' experiences.

4.8.3 Process of Narrative Analysis - The Voice Centered Relational Method

Narrative analysis was introduced by Labov and Waletzky in 1967 with their prescriptive and structured approach, which was designed,

> "for the analysis of oral versions of personal experiences in English" (Labov & Waletzky, 1967: 12)

Their method of analysis was grounded in linguistic traditions, and involved the re-capitulation of the participants' past experiences through the temporal sequencing of events (Labov et al., 1967). However Labov and Waletzky (1967) have been criticised that their method of analysis may lead to the fragmentation of the overall narrative and compromise its meaning (Mishler, 1986). Reissman (1993) supports Mishler's (1986) concern that fragmentation of the narrative can result in lost meaning (Reissman, 1993). Authors such as Reissman (1993), Mishler (1986) and Bell (1988), have consequently adapted Labov and Waletzky's (1967) structured method to overcome this issue. These authors also wanted to give greater appreciation to the role of the interviewer (Mishler, 1986), and to consider further both the content and structure of narrative (Bell, 1988). The VCRM analysis takes many of these issues into consideration; indeed a number of them are implicit within the method itself.

The VCRM narrative analysis originated from Brown and Gilligan's (1992) work into the lives of adolescent girls (Brown & Gilligan, 1992). It is a method which focuses on the participant's voice, and their relationships, which represents a considerable move away from Labov and Waletzky's (1967) prescriptive narrative analysis. Brown and Gilligan (1992) claimed that the method encompasses what is said, and unsaid by participants through listening as well as reading the transcript (Brown et al., 1992; Byrne, Canavan, & Millar, 2009). There is little discussion about the method in the literature and it is surprisingly underused, in both health care studies and within other disciplines – even in psychology where it originates.

Mauthner and Doucet (1998) both used the VCRM in their respective studies about maternal and domestic violence. In a reflective paper they describe the many advantages to using the method, and what they perceive as the disadvantages. Although they found it to be valuable overall, they described two major constraints. Firstly, it was massively time-consuming and secondly, the lack of definition of 'voice' caused problems (Mauthner & Doucet, 1998). The authors concluded that the VCRM uncovered stories/narratives in different voices – the story was told in one 'voice' by the participant, in a particular social context; yet heard by another voice, in another social context. Mauthner and Doucet (1998) suggested that reflexivity on the part of the researcher was the best way to deal with the potentially contentious issue of voice and context (Mauthner and Doucet, 1998).

The VCRM is set apart from other methods of narrative analysis due to its inclusive nature - the transcript is read as a whole, which eliminates the possibility of fragmenting the narrative. Other forms of narrative analysis are more prescriptive in nature, and have a tendency to fragment, and potentially decontextualise the narratives. Nevertheless, the VCRM is rarely used in studies relating to health care. Chapter two (page 33) highlighted that those with illness tell stories; they tell them to their doctor, to their family, to their friends, therefore a narrative approach is appropriate to explore the illness experience. VCRM will maintain the integrity of the participant's story as a whole and support me to focus on the context of story. The experience of illness is all encompassing; it is social; spiritual; psychological and physical, and the VCRM will facilitate the exploration of all four domains. Pinto (2004) commented that VCRM is useful for studies that involve dissociation and the fragmentation of stories and used the illness experience as an example of this (Pinto, 2004).

The VCRM involved four different readings of each interview transcript. Prior to commencing the baseline analysis I designed a template, which is based on the four readings as described by Brown and Gilligan (1992) so I could employ a structured

approach. This template can be found in figure four (page 96). Reading 1a was for overall plot; what story was the participant telling? Who were the characters? What events unfold over the course of the story? Reading 1b invites the researcher to share their thoughts and feelings about the interview. Reading two focuses on the active voice of the participant, and how they used pronouns in the text. Reading three explores how the participants spoke and saw themselves, within their relationships. The fourth and final reading is about context, and the wider social and cultural frameworks in which the stories are heard (Brown and Gilligan, 1992).

VCRM TEMPLATE FOR ANALYSIS (Brown and Gilligan, 1992)
1a) OVERALL PLOT - Listen to the overall story to get a sense of what is happening and the events which unfold over the course of the transcript
i)   Note the who, what, when, where and why of the narrative
ii)   Questions to pose of the narrative:
  - Are there recurring words?
  - Are there recurring images?
  - Is there a central metaphor?
  - What are the emotional resonances?
  - Are there contradictions within the narrative?
  - Are there inconsistencies in style?
  - Are there revisions and/or absences in the story?

1b) READER RESPONSE - We have to reflect on ourselves as people in the privileged position of interpreting the life events of another and consider the implications of this act
i)   Questions to aid reflection
  - In what ways do we identify with or distance ourselves from this person?
  - In what ways are our experiences different or the same?
  - Where are we confused or puzzled?
  - Where are we certain?
  - Are we upset or delighted by the story, amused or pleased, disturbed or angered?

2) THE VOICE OF 'I' - Allows the researcher to focus on the active voice of 'I' which is telling the story
  - How does the respondent experience, feel and speak about her/himself?
  - Are there changes in the use of 'I', 'we' which signals change in how the respondent perceives and experiences herself?

3) READING FOR RELATIONSHIPS - How does he/she experience herself in the relational landscape of human life?
Relationship with health service, spouse, GP, friends (alive or dead), family, relationship with self and body, time, the wider patient collective, other cancer victims, God or other higher being

4) SOCIAL, CULTURAL AND POLITICAL CONTEXTS - In what societal and cultural frameworks is this voice being heard and story being told?
What are the cultural contexts?
Cultural norms and expectations:
Social structures? Health care structures - expectations of health service? Gender, class, age, sexuality? Home structures?

Figure 4. Template of VCRM of analysis, Adapted from Brown and Gilligan (1992) Chapter 2. The Harmonics of Relationship

4.8.3.1 Narrative longitudinal analysis

The longitudinal narrative analysis was carried out after all three interviews and the individual VCRM analyses had been completed for each participant. I adopted a case history form, which enabled me to tell the participants' stories (Thomson, 2007a). The main focus throughout the longitudinal narrative analysis was on change. What changed over time? How did the participants' experience and speak of themselves change over time? Which characters came in and out of the story and who was constant? In what way did the socio-cultural contexts in which the story was told change over time? Soon after commencing the first analysis, the challenge of describing someone else's story became evident. In order to alleviate some of my concerns about how to keep the integrity of each story intact, I was consistently guided by the data, through listening to the audio-recordings again (sometimes several times) and re-reading the transcripts.

Before starting the formal longitudinal analysis I re-read each participant's transcripts and the corresponding VCRM analysis for the interviews at Time 1 (T1), Time 2 (T2) and Time 3 (T3) in order to gain a sense of the overall picture. I found it necessary to read each transcript consecutively, in one sitting to get a feel for the pace of the story, and how it flowed. Then I fashioned a diagrammatical interpretation of the participant's story. The X axis represented the time, and the Y axis each of the four readings – overall plot, voice of 'I', relationships and socio-cultural contexts.   This diagram allowed me to see what had changed over time, but also how the themes overlapped and interconnected with each other.   Furthermore, this technique gave me clarity on the participant's journey.

The next step in the narrative longitudinal analysis was to make sense of the group as a whole. Were there common themes displayed within the group? To do this I constructed another diagrammatical timeline, but a simplified version of the first. I placed a straight line across a sheet of A4 paper which represented time. I then demarcated the line with the month that the interview/telephone call was carried out. Above the line I used boxes

to note the key events from the overall plot, and the time they occurred, and below the line the key themes (from readings two to four) which related to that time point. In addition, I added my reflections from the analysis to the diagram, as suggested by reading 1b. Then I drew each timeline in PowerPoint with a colour coding scheme to represent the themes, so I could see at a glance those that had changed over time. Some of these timelines are presented in chapter seven (page 177). Overall, this diagram enabled me to identify common themes among the cases. The use of such graphic representation for QL analysis is innovative, particularly in health care research, and thus I discuss this further in chapter nine.

4.8.4 Process of Thematic analysis

The method of thematic analysis that I adopted in this study, is based on the coding principles for grounded theory analysis as described by Charmaz (2006). To guide me in moving beyond the initial coding stage I latterly consulted the work of Ziebland and McPherson (2006).

4.8.4.1 Coding

Initial coding marked the first stage of thematic analysis. Prior to subjecting the baseline interview transcripts to any thematic analysis, I devised a rudimentary coding framework which comprised of approximately ten codes which featured the major topics from the interview schedule which can be found in appendix five (page 302). Although starting with a very basic coding framework, I sought to code from the data, thus adhering to the method carried out by grounded theorists. I then systematically coded the individual interview transcripts and further codes were derived from the data. For the initial stage, I started by coding each transcript on a line by line basis (Charmaz, 2006). However, as the interviews were in a narrative form, where participants told their own stories; it was often more appropriate to categorise the data based on the incidents that participants described. Whilst grounded theorists prefer line by line coding

methods, I considered that the incident to incident method would facilitate comparison between the narrative and thematic analyses later in the process.

This initial coding framework consisted of approximately 150 single codes, but after defining and re-naming the codes - based on the data they contained - this list was shortened to 72 codes. These 72 codes were grouped hierarchically according to the following headings; carer issues, communication, finance, methodology, palliative/terminal/incurable (*in vivo* code – where the participant actually used the word), personal responsibility, physical (included diagnosis), psychological, service provision, social, societal, spiritual and temporal. The development of the coding framework was a necessary and very useful stage which ensured that the data were in a workable form before embarking on the next step.

The coding practices were the same for the T2 and T3 thematic analyses but I started with the coding framework from the previous round and added a new heading entitled 'new nodes', which included new codes which had not arisen in the previous analysis. This technique ensured the iterative approach which is required in grounded theory analysis and indeed, longitudinal analysis. Additionally, this enabled me to better compare the codes which arose across time points for the longitudinal analysis. The coding framework from each of the three time points can be found in appendix eight (page 305).

After completion of the initial coding stage, I summarised the issues raised in the data from each code, which is known as focused coding (Charmaz 2006). The aim of this focused stage is to describe and summarise what is happening in the data. In order to help me organise and operationalise this stage efficiently, I consulted Ziebland and McPherson's (2006) experiences of carrying out qualitative thematic analysis (Ziebland & McPherson, 2006). As they suggested, I devised a 'one sheet of paper' (OSOP) method where I noted all the issues that were raised in the coded extracts for each node.

As I read through pages of coded extracts, I noted each of the issues that the participants were talking about, and the unique participant identification code, so I could easily refer back to the data and, in so doing, remain close to the source (Charmaz, 2006). An example of this focused coding technique, using the OSOP method from the baseline analysis can be found in appendix nine (page 307).

The third stage, is that of axial coding which refers to the development of the broader themes which take account of the issues raised through focused coding (Charmaz, 2006). For each code that had been subjected to focused coding, I took the OSOP containing the issues raised by the coded extracts, and the ID numbers, and posed the question 'what is going on in the data that explains these issues?' (Ziebland et al., 2006). The number of basic themes that arose from each code was dependent on its size, and more obviously the number of issues raised in the coded extracts. Some of these broad themes can be seen as they emerged on the OSOP in appendix nine (page 307). The final stage, known as theoretical coding is about answering the why question and this happened during the longitudinal analysis and through the writing.

4.8.4.2 Longitudinal thematic analysis

As the coding section above (page 98) suggests, I used the coding framework from the previous interview to inform the analysis of the subsequent interviews. This insured an iterative approach but also allowed for a comparison of the new codes which were arising from one time point to the next. I was influenced by Saldana's (2003) framework from his widely cited text on QL analysis, which was presented in chapter three (page 47). Although I had proposed to answer each of Saldana's (2003) questions step by step, the reality was that the focus became on the idea of the through-line. This was the result of the fact that the longitudinal narrative analysis had already been conducted. I discuss this further in chapter nine.

4.8.5 Analysing Field notes

As I described in section 4.7.4, I wrote detailed field notes from the interviews and from every telephone call with the participants in the flexible group. As the telephone calls were not audio-recorded, these field notes were the main source of data. In order to analyse them, I first collated them, and then re-read them one after the other whilst noting the various issues participants were discussing. I also considered the methodological and theoretical notes I had made, many of which have contributed to the writing of this thesis. In reflection, these field notes were a necessary tool in this longitudinal study, given the number of interviews and telephone calls which occurred over time. Excerpts of the field notes are used in chapter eight.

4.8.6 Feedback to participants

Providing feedback to participants in the context of this PhD study is a complex issue, as many of the participants died during the study, and several following completion of the interviews. This study also recruited some informal carers but this is also problematic, as it may be upsetting for them to be reminded of the experience of their loved one. Therefore, I propose to give the patients who are still alive and the carers who participated in the study the option to review the findings.

Given this complex situation I feel an even greater responsibility to give the participants in this study a voice. Therefore I aim to write a paper which reports the experience of metastatic colorectal cancer.

4.9 Reflexivity in qualitative research

Mishler (1986) suggested that the narrative interview is a co-construction between the researcher and researched and therefore I must reflect upon my position in the research process. Reflexivity is a fundamental aspect of qualitative research practice and according to Finlay (2002) involves,

"examining how the researcher and intersubjective elements impinge on, and even transform, research" (Finlay, 2002: 210).

Reflexive practice encourages transparency, trustworthiness and accountability in research practice which are key elements for assessing the quality of research (Finlay, 2002). According to Finlay (2003) reflexivity can be a valuable tool to:

- Examine the impact of position, perspective and presence of researcher
- Promote rich insight through examining personal responses and interpersonal dynamics
- Open up unconscious motivations and implicit biases in the researcher's approach
- Empower others by opening up a more radical consciousness
- Evaluate the research process, method and outcomes (Finlay, 2003: 16)

Finlay's (2003) typology for reflexivity in contemporary qualitative research practice proposes 5 forms; introspection, intersubjective reflection, mutual collaboration, social critique and ironic deconstruction. I found affiliation with reflexivity as mutual collaboration, which Finlay (2003) defines as, reflexivity which,

"offers the opportunity to hear, and take into account, multiple voices and conflicting positions" (Finlay, 2003: 12).

The focus on multiple voices is particularly relevant for this PhD study given the narrative methodology and the use of the VCRM. Moreover, QLR stimulates reflexivity on the part of the participant, as it provides the participant with ample time to reflect, and if required, re-evaluate their experiences. As such, it seems logical to consider both the reflexive opportunities of the researcher and the participant (Jorgenson, 1991; Arvay, 2003).

4.9.1 Reflexive data generation

How participants perceived my role varied within the sample, as did their awareness of the self I brought to the research – the fact that I was young and female[13]. Participants inferred that I should not be doing this PhD as they feared the impact of my engagement with such emotionally demanding stories. Although I took the opportunity to reassure them that I had a great deal of support in the workplace, I do suppose that this influenced the stories that participants wished to tell and those they wished to withhold. I used my field notes and interview summaries to share some these thoughts as they occurred. Likewise, I used the field notes to reflect on my practice of interviewing. For example, I noticed early on, after listening to the first ever interview that I had a propensity to talk through the natural silences in conversation, so in the interviews that followed I allowed these silences to evolve naturally. In so doing, the participants were able to tell me their own stories in their own words. This is an example of how reflexivity changed my practice.

4.9.2 Reflexive data analysis and interpretation

As Mauthner and Doucet (2003) suggested, Brown and Gilligan's (1992) VCRM provides an instrument to achieve reflexive data analysis and interpretation. Reading 1b entitled Reader Response, invites the researcher to specifically reflect on their position in the research process, which constructs a dedicated space within the analysis for engagement with my stance (Brown et al., 1992). The interpretation of participants' narratives is, as Brown and Gilligan (1992) described, 'a privileged position', hence the importance of reflecting on our emotional, intellectual and social positions (Mauthner & Doucet, 2003). So how does this translate to the reflexive practice of analysis and interpretation? The purpose of reflexive practice is to ensure transparency, trustworthiness, and accountability in research and therefore researchers need to be clear

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[13] Reinharz (1997) argued that there are three broad selves who co-exist throughout the research project. The brought self, the research self and the sectionally-created self.

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about their motivations for the research and aware of making false claims from the findings (Doucet, 2008). False claims could result in unethical practice and unsubstantiated recommendations for future research and practice. In terms of my own analytical practice, I had to be clear about my background as a nurse and how this might influence my interpretation of the narratives I was hearing. On one hand, I might experience anger when I heard a story about a participant feeling neglected and abandoned by their health professionals, yet on the other hand I was aware of the constraints on health professionals in terms of time and resources.

4.9.3 Different Selves

The discussion around the presentation of different selves relates to how I was perceived by those in the academic setting and in the field. Since commencing this PhD I have wrestled with my *self* as the nurse, and my *self* as the researcher. In the early days of the study I failed to realise that this dual role was one of strength, particularly as I needed to network in the clinical setting, where I would be recruiting participants. My understanding of the way the clinic functioned, my familiarity with medical notes, and my ability to give only the necessary information to busy health professionals was advantageous. My experience finds support in that of Ritchie (2009), who described her experiences of interviewing older people about their medication-taking beliefs and practices. Like me, Ritchie was both a nurse and a researcher and she identified with managing the two complementary personas (Ritchie, 2009).

Reinharz (1997) argued the existence of three broad categories of self, which co-exist throughout the research process and thus must be reflected upon; the research self (me as the researcher), the brought self (in my case nurse, young, female, wife) and the sectionally created self (friend, companion, shoulder to cry on) (Reinharz, 1997). Throughout this PhD I have experienced myself as the researcher, myself as the nurse and my personal self. The longitudinal nature of the study meant that over time, my professional identity became less present and my personal identity more present in my

relationships with the participants. This raised some ethical questions relating to the research process which was also described by Swartz (2011), following her experiences of conducting ethnographic research (Swartz, 2011). For example, over the course of this study I have considered the aptness of 'giving something back' to participants, when they inevitably asked about my personal life; my background, marital status or family – in other words, how to engage with the sectionally created self. This issue is exaggerated in QLR because of the need to form, and maintain relationships with participants. I believe forming a relationship through the natural, everyday medium of conversation (whether interview, telephone conversation or brief chance encounter) plays a vital role in the QLR process. If nurtured, the flourishing research relationship can, as Swartz (2011) also described, encourage private accounts to emerge in data, earlier than they may have done otherwise, and improve the potentially therapeutic outcome of the research for the participants (Swartz, 2011).

4.10 Concluding remarks

In this chapter I have situated this study within a theoretical framework, and have described the conduct to ensure there is transparency in the methods I used to generate and analyse the data. Although this account implies a seemingly straightforward experience I incurred problems with recruitment, faced the challenge of how to analyse the vast volume of data to capture time, process and change and dealt with a number of ethical problems. I share my experiences and detail these difficulties throughout this thesis. In spite of these challenges, I eventually recruited 16 patients and eight of their carers into the study. Data were generated from narrative interviews with these participants, and the transcripts subjected to both narrative and thematic analyses. I concluded this chapter with a discussion of how I engaged with my reflexive self throughout the research.

CHAPTER FIVE
The participants and the interviews

5.1 Introduction

Due to the complex chronology of this longitudinal study; where the participants were interviewed at different time points, with or without an informal carer; the purpose of this short chapter is to describe the sample. I provide an overview of the sample, and the number of interviews that were conducted at each time point. I conclude this chapter with an outline of the chronology of interview and telephone calls for each participant.

5.2 The participants

Demographic information of the participants in the six monthly interval group, and the flexible interval group can be found in tables three (page 108) and four (109) respectively[14]. Chapter four, section 4.5.2 (page 74) described how each participant was assigned a pseudonym. This pseudonym is used in the tables to follow. In total there were 16 patients (ten men; six women) and eight of their carers (one male; seven female). In each of the two groups; six monthly and flexible interval respectively, there were a total of five men and three women. This proportion is consistent with the Information Services Division ISD, Scotland figures which suggest that of the individuals who get colorectal cancer 63% of those will be male (Information Services Division, 2010). The age of the patient group ranged from 48 years to 80 years at the time of recruitment. The age of the carers was not recorded. Six of the eight carers were spouses and two were siblings.

The anatomical location of the primary colorectal cancer, and of the metastases is reported in tables three and four. Only one participant had been diagnosed with a rectal tumour. The time from diagnosis of the metastases, to recruitment into the study ranged

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[14] BER is used to describe the bereavement interviews which were conducted at T3.

from two months to 15 months. The exact month of the diagnosis of Brian's metastatic disease was difficult to determine because of missing information in the medical notes. However, I was assured by the health professionals at the recruiting centre that the time between the metastatic diagnosis and his recruitment was less than 18 months, which is consistent with the inclusion criteria in section 4.6.2.1 of chapter four (page 77). All the participants had been told that the cancer could not be cured. At the end of the data generation phase of this study, nine of the 16 patients had passed away and seven patients were still alive. In the months that followed the completion of the data generation phase, I heard that four of those remaining patients had also passed away.

Group (interval)	Participant pseudonym	Carer pseudonym/relationship (if recruited)	Age at recruitment (years)	Diagnosis (primary/metastatic)	Months from diagnosis of metastatic disease to recruitment	Interviews conducted	Individual or joint interview with carer	Status at study end
Six month	Ann	No carer recruited	67	Colon/peritoneal metastases	2	T1, T2, T3	N/A	Surviving
Six month	Brenda	Len (spouse)	60	Colon/liver metastases	6	T1, T2BER, T3BER	Joint/carer only	Deceased
Six month	Andrew	Gill (sister)	57	Colon/liver metastases	9	T1, T2, T3	Joint	Surviving
Six month	Brian	No carer recruited	59	Colon/liver and lung metastases	<18 months	T1, T2, T3	N/A	Surviving
Six month	Cath	No carer recruited	48	Colon/liver and peritoneal metastases	15	T1, T2	N/A	Hospice, T3 abandoned
Six month	Chris	Hazel (spouse)	80	Colon/lung and liver metastases	13	T1, T2, T3	Joint	Surviving
Six month	Duncan	No carer recruited	59	Rectal/liver metastases	10	T1, T2	N/A	Deceased
Six month	Edward	Iris (spouse)	74	Colon/peritoneal metastases	7	T1	Joint	Deceased

Table 3. Participant demographics and number of interviews for the six monthly interval group.

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Group (interval)	Participant pseudonym	Carer pseudonym/relationship (if recruited)	Age at recruitment (years)	Diagnosis (primary/metastatic)	Months from diagnosis of metastatic disease to recruitment	Interviews conducted	Individual or joint interview with carer	Status at study end
Variable	Fred	Jane (spouse)	73	Colon/lung and liver metastases	13	T1	Joint	Deceased
Variable	Gordon	Kate (spouse)	65	Colon/liver metastases	6	T1, T2, T3	Joint	Surviving
Variable	Deirdre	No carer recruited	66	Colon/cervical and vaginal metastases	5	T1, T2	N/A	Deceased
Variable	Harry	Lily (spouse)	76	Colon/liver metastases	12	T1, T2, T3BER	Joint/carer only	Deceased
Variable	Eve	No carer recruited	62	Colon/lung and liver metastases	6	T1, T2	N/A	Deceased
Variable	Ian	No carer recruited	65	Colon/liver metastases	2	T1, T2, T3	N/A	Surviving
Variable	John	Mary (sister)	62	Colon/liver metastases	11	T1, T2, T3BER	Individual	Deceased
Variable	Faye	No carer recruited	55	Colon/lung and liver metastases	9	T1, T2, T3	N/A	Surviving

Table 4. Participant demographics and number of interviews for the variable interval group

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5.3 Location and timing of the interviews

Where possible, interviews were conducted in participants' homes. This was the preferable approach, as I found participants to be more relaxed in their own surroundings. Furthermore, extra trips to the hospital for many would have been an inconvenience, and several of the participants who were approached at the clinic, were eager to participate when informed that I would visit them in their homes. Having said this, two participants, although keen to participate requested that the interviews were carried out in the hospital for personal reasons. Duncan lived with his octogenarian father and he did not want him to know about his participation in the study. Eve was often away from home so it was more convenient for her to meet at the hospital. I was allocated a small room near the clinic which was quiet, and for the duration of the interviews conducted there the participants and I were uninterrupted. Both participants were interviewed at T1 and T2 in the hospital.

Several of the participants remained employed throughout the study so I was flexible about the timing of interviews, and carried out several interviews in the evening. Involving informal carers in the study also meant that it was critical to be flexible, as in some situations the carers were also employed. All interviews were arranged by telephone, approximately one to two weeks before the planned date.

Table five (page 111) displays the number of interviews that were conducted at each time point and includes a breakdown of the number of joint (patient and informal carer) and individual (patient OR carer) interviews.

	Time 1	Time 2	Time 3
Individual patient interviews	9	9	4
Joint patient and carer interviews	7	4	3
Total number of patient interviews	**16**	**13**	**7**
Individual carer interviews	1	1	3 (bereavement interviews)
Total number of interviews	**17**	**14**	**10**

Table 5. Number of interviews conducted at each time point

5.3.1 The first interview (T1)

A total of 17 face to face interviews were conducted at T1. There were 16 patient interviews (nine were individual patient interviews; seven were joint patient and carer interviews). There was one individual carer interview with a sibling of the patient. The interviews lasted between 45 and 120 minutes for the individual interviews, and 60 and 90 minutes for the joint interviews.

5.3.2 The second interview (T2)

A total of 14 face to face interviews were conducted at T2 and of these, 13 were patient interviews (nine were individual patient interviews; four were joint patient and carer interviews). There was one individual carer interview with Len, whose wife Brenda was in hospital at the time of the interview. All but one of the 14 interviews were conducted six months after the first. Eve was in the flexible interval group and had taken ill, so we met for the second interview just two months after the first. Ann was interviewed at month ten of the study as she incurred a prolonged stay in hospital between T1 and T2. The T2 interviews lasted between 25 and 120 minutes for the individual interviews, and 30 and 120 minutes for the joint interviews. The same two participants asked that the interviews be conducted at the hospital rather than their homes. As the crosses on figure five (page 114) below illustrate, two participants died between T1 and T2, and their

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spouses, who had participated at T1 declined to participate in a bereavement interview as they felt it was the wrong time.

5.3.3 The third interview (T3)

A total of ten interviews were conducted at T3 and of these, seven were patient interviews (four were individual patient interviews; three were joint interviews with the patient and the carer). As the crosses on figure five (page 114) below illustrates, six participants died between T2 and T3 and I conducted one interview with Faye at month nine of the study as she had news that she only had a few weeks to live. The interviews at T3 lasted between 25 and 45 minutes for the individual patient interviews and 30 and 90 minutes for the joint interviews.

5.3.3.1 Bereavement interviews

Bereavement interviews were conducted with three carers at T3, as the red circles on figure five (page 114) illustrate. The bereavement interviews lasted between 35 and 50 minutes. Two carers declined to participate in bereavement interviews at T2. Iris, Edward's wife, and Jane, Fred's wife declined to participate because they were still grieving.

Figure five (page 114) illustrates the timing and schedule of the interviews/telephone calls for each individual participant. Where joint interviews were conducted, I have constructed the timeline for the dyad. John and Mary, brother and sister chose to be interviewed separately so I have constructed a timeline for each. The timeline shows; the month of the study, when the face to face interviews were conducted, when the telephone interviews were conducted, when the patient died, and when a bereavement interview was carried out. Note that only two interviews were conducted with Mary, at baseline and at month 12. This was because I was unable to make contact with her at month six of the study as she worked full time in a very busy job and had a family of her own.

5.3.4 Telephone calls

As figure five (page 114) shows, monthly telephone calls were conducted with patients in the flexible interval group. These calls lasted between five minutes and approximately 40 minutes. All these telephone calls were carried out in my office at The University of Edinburgh. These informal telephone interviews were not recorded, rather detailed field notes were written, as I outlined in chapter four.

5.4 Concluding remarks

In this chapter I have introduced the group of participants, both patients and carers who took part in this study. In tables three (page 108) and four (page 109) I presented the demographics of the six monthly interval group and the variable group respectively. In table five (page 111) I detailed the number of interviews that were conducted at each time point. Figure five (page 114) shows the chronology of the individual interviews and the telephone calls, and marks the death of the participants that passed away during the course of the study.
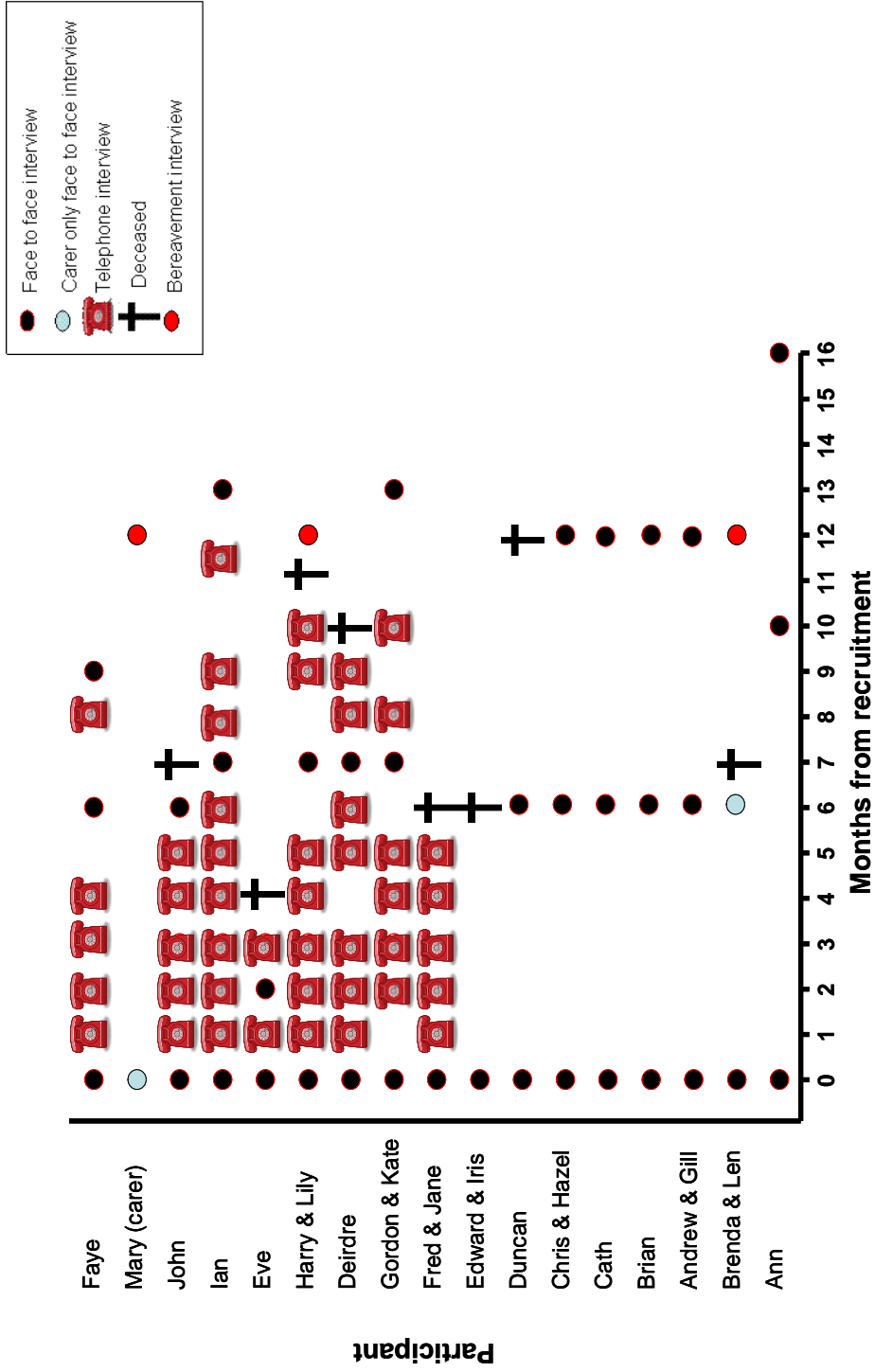
Figure 5. Chronology of participant interviews, telephone calls and deaths

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CHAPTER SIX
The beginning, the middle, and the end

6.1 Introduction

In the three findings chapters to follow I consider the opportunities that QL interviewing presents for understanding the experiences of those with metastatic CRC over time. The chapters broadly reflect the three tenets of QLR which are time, process and change (Holland et al., 2006). In this chapter I examine the accounts of the participants' experience of metastatic colorectal cancer from each time point. In so doing I examine how the experiences of the group as a whole changed across time – time being the first key feature of QLR.

This chapter will be divided into two parts. In part I, I present the themes that arose across the cases for each time point (Time 1 = T1, Time 2 = T2, Time 3 = T3). As I described in chapter four, after each wave of interviewing was complete I wrote a summary narrative and summary thematic analysis. The coding framework from the thematic analysis of each time point can be found in appendix eight (page 305). The findings in this chapter are based on an amalgamation of the thematic and narrative analyses of the individual cases at each time point. In part II, I give an overview of how the themes changed across time and the broad narrative threads that describe the data. I also consider if the concept of liminality can be applied to describe the experience of metastatic CRC.

6.2 Part I – Across case themes at each time point

6.2.1 The first interview (T1)

I described in the methods chapter that I commenced every interview by asking the participant to tell me what had happened to them. This meant I heard their accounts as

they wanted them to be understood. The themes to follow emerged from the 17 interviews that were carried out at T1. I conducted 16 patient interviews (nine individual patient interviews; seven joint patient and carer interviews) and one individual carer interview.

6.2.1.1 The diagnosis story (The Beginning)

At the first interview all the participants narrated their diagnosis story. The flow chart in figure six summarises the clinical story that the participants described.
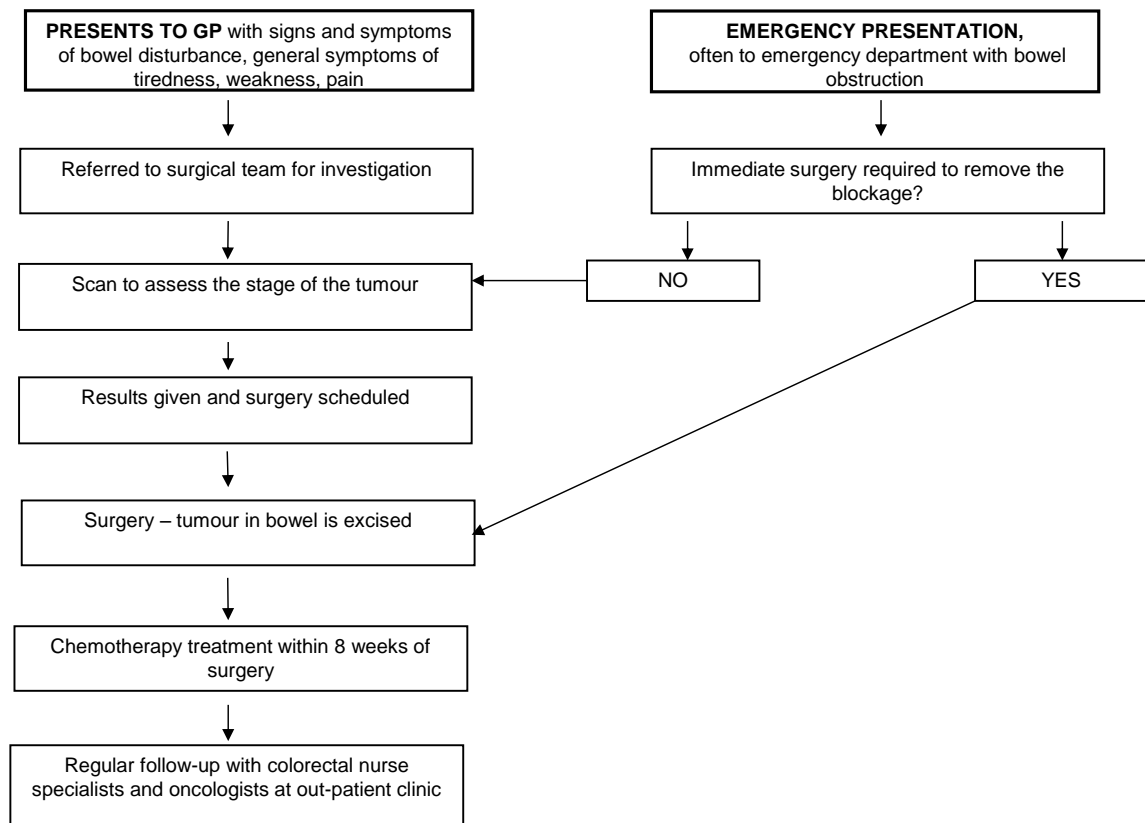
Figure 6. Flowchart representing the diagnosis story

As figure six suggests, participants reached specialist cancer care in one of two ways. There were participants who presented to their GP. They experienced tiredness, rectal bleeding, constipation and bloating. Often the onset was fairly insidious, as the quote below reflects Ann's diagnosis story.

"when we were in Rome I was getting very tired *(Right)*You know, I mean I would get sore feet, sore legs I just have to sit down every so often. Going up stairs was a problem, you know I was very tired. But I was swimming every day, more or less here so I hadn't noticed it so maybe it was coincidence. Anyway round about Jan I noticed there was a change in my bowel habit, you know I was having to go more often and so on and I went to my GP who, dear em, said em said em, eh, gave me a rectal examination and said she didn't feel anything but she's fine but of course eh how far up does a finger go? *(yeah)* and eh she said it's probably just diverticulitis. Yes, she said you've probably just got diverticulitis or diverticular disease, she says very, very common in people your age but would you like me to refer you for another opinion. Now you know, to my terrible regret I said no. That was in January 2005 *(right)*. Right, so I said no it's all right and I did think about it but I said no I won't. Round about March or April, March, April I was having more problems *(OK)* so I went back to her and said look I'm not happy I want to be referred. So I was to be referred to the infirmary or the Western rather, and I was told it would be at least 18 week waiting time it would be, and I was beginning to get a bit mmmmm itchy by this time because there was obviously something wrong. So I got in touch with the [private hospital] and I went out there and saw [consultant surgeon]" (Ann, 67 year old female, patient, time 1)

Ann's diagnosis story about misdiagnosis was not uncommon. For a number of the participants the referral process was stressful, lengthy and often led to feelings of abandonment and fear. For example, in the quotes to follow Harry and his wife Lily had a hunch that something more serious was wrong but found that nobody would listen.

"I knew for bloody ages there was something wrong with me. I knew" (Harry, 74 year old male, patient, time 1)

"He tried to tell our doctor eh he felt as if what he was eating wasn't going down so there was something there but nobody would listen to him" (Lily, female, wife and carer, time 1)

However delays in the referral process were largely due to administration problems. For example one participant was advised by his GP to see a surgeon privately to speed up the referral. Ann decided to seek a private opinion to speed up the process as did Gordon, as the quote below suggests.

"the problem is the [hospital], their admin area is just repulsive so you'll never get an appointment so he suggested going to the [private hospital]" (Gordon, 65 year old male, patient, time 1)

Ann, like Gordon was left wondering if the delay may have resulted in more extensive disease, as the quote below illustrates.

"Would 3 months have made any difference? Who knows" (Ann, 67 year old, patient, time 1)

Other participants presented to the hospital as an emergency because the tumour was obstructing the normal function of the bowel. The participants in this group generally

required urgent surgery to remove the blockage. In comparison to the insidious onset of the experiences of those in the first group this was often a sudden presentation.

As figure six (page 116) highlights, surgery followed by chemotherapy was the course of treatment for all the participants, with the exception of Duncan who did not undergo surgery, but did receive chemotherapy. Some participants presented with metastatic colorectal cancer and others developed metastatic disease following the initial diagnosis. In this latter group, the diagnosis story consisted of two parts, the first was generally the initial cancer diagnosis and the second was the metastatic diagnosis. Overall participants expressed an understanding that their disease was incurable, although only a few participants used the word palliative or terminal. The quotes below illustrate Brenda and Ian's respective understandings of their disease.

> "I've really had to say it to myself quite often is that it's never really going to go away" (Brenda, 60 year old female, patient, time 1)

> "one of the letters there saying that it's no erm, there's nothing else they can do erm so wherever it was, no that one, no that one. There it's there. Not curative see" (Ian, 65 year old male, patient, time 1)

6.2.1.1.1 Form of the diagnosis stories

The form of the diagnosis stories differed, and I identified four different styles of storytelling.

1) In the first, and most frequently used of these styles participants described their diagnosis using a temporally ordered sequence of events and the story generally started from the time they experienced any pain or any irregularities related to their bowels. For example, participants described experiencing bleeding from their bowels, bloating and irregular bowel movements or for a few participants the signs were more general, for example flu-like symptoms or extreme tiredness. They then described how the official diagnosis was made – colonoscopy, CT scan, blood tests and how the diagnosis was communicated to them by the oncologist or surgeon. If the cancer had recurred and

metastasised after the original diagnosis[15] they also described how this became apparent, was identified, diagnosed and communicated to them. Participants then described the surgical and chemotherapy treatment and concluded with a synopsis of their situation at the time of the interview – participants were usually between chemotherapy regimens, awaiting a scan or awaiting a clinic appointment. Participants usually described any other illnesses, or lack thereof during the diagnosis story, which situated the cancer within their wider biography.

2) The second type of diagnosis story was similar to the first, but the two participants started their diagnosis story from the beginning of their illness career. Narrating the story in this way emphasised the impact that chronic illness had on their lives, but also immediately contextualised the cancer experience. For example, John's diagnosis story began with him narrating his diagnosis of coronary heart disease (CHD)[16] and diabetes 20 years earlier hence, for the most part he considered the cancer another chronic illness. The beginning of John's interview resembled a medical consultation, where the patient would describe their medical history. Likewise, my field notes remind me that before I had turned on the digital recorder, Ian had been telling me about his diagnosis of Parkinson's disease many years earlier. These men had already adapted their lives to encompass their respective illnesses.

3) Two interviews can be categorised in the third style of diagnosis story. These stories started with a description of the participants' current situation and concluded with the events that led to the diagnosis. In other words the story was told backwards, which gave greater emphasis to the participants' current problems. For example, Brenda and her husband Len who participated in a joint interview described the diagnosis story in

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[15] As opposed to being diagnosed with colorectal cancer and metastases simultaneously.

[16] CHD is caused by the build up of plaque on the arteries to the heart which cause them to narrow thus limit the supply of oxygen and blood to the heart. www.nlm.nih.gov/medlineplus/ency/article/007115.htm accessed 22/08/2012

this way and they demarcated their journey by signposting the events that had led to their current situation. Likewise, Eve commenced the interview talking about chemotherapy which she was receiving at the time and was causing her much distress, and worked back to the initial diagnosis.

4) Participants in the fourth and final category described the diagnosis story as just a small sub-narrative within the overall story. The two participants in this group – both male - placed greater meaning and significance on the other illnesses or ailments which affected the quality of their lives more than the cancer. For example Fred, who was interviewed with his wife Jane reflected on the disruption caused by chronic obstructive pulmonary disease (COPD)[17], rather than on the disruption caused by the cancer. Similarly, Harry aged 76 years, had incurred a long stay in intensive care when he was first diagnosed was more concerned with the musculo-skeletal impairment and mild memory loss he had suffered as a result. Like Fred, these issues affected Harry's daily living and his ability to perform simple tasks meaning the cancer was less of an everyday issue.

6.2.1.1.2 Coming to terms with the diagnosis

6.2.1.1.2.1 Shock

Participants also shared their emotional responses to the diagnosis. Some were extremely shocked by the diagnosis; for example Duncan thought that bowel cancer was far down the list of things that might be wrong with him when he first started experiencing symptoms. The quote below illustrates this. Duncan's shock was amplified as he kept fit, and although confessed to sometimes eating junk food he felt he was generally healthy.

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[17] COPD is a lung disease which is characterised by the obstruction of airflow to the lungs which causes cough, breathlessness and sputum. www.who.int/respiratory/copd/definition/en/index.html, accessed 22/08/2012

"had an appointment with Prof{surgeon} (right), had the tests and whatever else erm and then I was told to get a CT and MRI scan. I think they must have guessed at the time, or had a fair idea of what it was but I never (right) although I have a partner whose daughter is a nurse (right) and she looked it up on the computer, the symptoms and said well it could be this, this, this and cancer was the last one on the list (right) I think it was 6 things it could have been" (Duncan, 57 year old male, patient, time 1)

Ian also described feeling shocked and like Duncan, he too thought that his healthy lifestyle made getting cancer less likely.

"not a clue about having cancer. It's no in ma body to have it. I mean I'm too fit" (Ian, 65 year old male, patient, time 1)

Faye, like Duncan and Ian was also shocked. Although she had a hunch that something was wrong with her she did not think that she had cancer.

"I knew there was something going on inside my body but erm I never thought it would be bowel cancer" (Faye, 55 year old female, patient, time 1)

Likewise Eve knew there was something was wrong but she was not expecting cancer.

"until you get diagnosed you don't, well you know there's something wrong but you don't really know what it is and you're not expecting it to be cancer" (Eve, 62 year old female, patient, time 1)

There were a number of participants who had a hunch that there was something more sinister wrong with them. For example, Brenda described that she knew they were going to tell her she had cancer although she still described being shocked when she was finally given a confirmed diagnosis.

"I knew, I knew well before they tell me I had cancer that I had it" (Brenda, 60 year old female, patient, time 1)

Those who went on to develop metastatic disease[18] described disbelief. Deirdre described her extreme shock and dismay when she was given the news that the cancer had spread and moreover that it was so extensive and thus incurable.

"Oh a shock, I was absolutely gob smacked I mean I knew it was there but I never expected it to be so extensive" (Deirdre, 66 year old female, patient, time 1)

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[18] In contrast to being diagnosed with metastatic disease at the outset.

In addition to the shock that participants reported, some imagined the metastatic disease spreading over their body. Len, Brenda's husband described the cancer taking over her body when he was talking about the extent of Brenda's metastatic disease. In the quote to follow, Deirdre illustrates the spread of the disease by imagining it taking over her body, bit by bit; organ by organ.

> "It's starting from the top and going down so a tiny bit in the lung, there's a tumour on the tube from the bladder, the kidney to the bladder, it's in the liver, it's in the cervix and it's in the vagina" (Deirdre, 66 year old female, time 1)

6.2.1.1.2.2 Sharing the news

Gordon knew himself that he had cancer, as did his wife Kate, but interestingly it was only at the interview that they vocalised their fears about how their future might look, as the quote below illustrates. Gordon and Kate did not want to cause excessive worry by talking to one another and Gordon did not want to upset his daughter by giving her the details of what should happen in the event of his death. This was not an unfamiliar story and it highlights the challenges that the participants faced in communicating the diagnosis to others. Participants often described an overwhelming need to protect their loved ones.

> "Kate   It was quite tricky though because I didn't know how much he was actually taking on and he maybe wasn't wanting to say, I don't know why you would think that I wouldn't have noticed but I certainly thought more than said I think.
> Gordon   From, probably from when I first saw Dr{surgeon} I had suspicions then
> Kate   Yeah you were going around changing all the things into joint names I noticed. All the financial things. Every day there was something else to sign, moving things over and I thought oooops
> Gordon   Just playing safe, just playing safe
> Kate   Making sure that everything will be ok?
> Gordon   Why not, why not
> Kate   Exactly so I knew that you were thinking along these lines but we weren't actually saying anything
> Gordon   You don't know this as well but I made out a list for {daughter} if anything happened. Our daughter is a solicitor so I made out a list, it's in the cupboard there so if anything happened to me just give this to {daughter}" (Gordon, 65 year old male, patient and Kate, wife and carer, time 1)

6.2.1.2 Experiences of treatment – surgery and chemotherapy

Another feature of the diagnosis narrative was the experience of treatment. Most participants had endured major surgery to remove the primary tumour in the bowel, and had subsequently been treated with chemotherapy[19]. A number of the participants were experiencing treatment at the time of the first interview meaning that I had to be acutely aware of participants getting tired or feeling ill during the interview. For some participants, surgery was considered a turning point. For example, Gordon had known that there was something wrong with him for some time so getting the surgery was a relief and a positive turning point.

> "Anyway so I had the operation the next day and from then on I've never looked back. Eh I really, the day before the operation I couldn't look at food the day after the operation I was feeling hungry" (Gordon, 65 year old male, patient, time 1)

However, for others the surgery was just the beginning of a long road to recovery. Moreover the emergency nature of the surgery in some cases, when the position of the tumour meant that the bowel was obstructed, meant that participants described being suddenly confronted with their own mortality, as this quote from Brenda illustrates.

> "Die or don't. That's how bad it was, if you don't get it you could die and if you do get it you could die. So what choice do you have?" (Brenda, 60 year old female, patient, time 1)

Likewise, the carers had to prepare for the possibility that the patient may die, as Lily described when she told me about Harry's admission to the hospital.

> "I went in on the Sunday and the doctor said I want to speak to you. She said your husband needs another operation. If he doesn't have it he could die and if he has it he might die and something, there was something leaking so he had to have the operation" (Lily, female, wife and carer, time 1)

Moreover, the type of surgery that participants received was dependent on the location of the bowel tumour. The location of the surgery meant the difference between having a permanent stoma bag or not. Only one participant in the study had a permanent stoma. However, most participants were warned about the possibility of needing a permanent

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[19] Whether surgery was possible or not was dependent on a number of factors which included; the location of the tumour, the location of the metastases and the underlying health of the participant.

stoma prior to receiving surgery. Their relief when they were told that they did not require a stoma was evident in the interviews, as the quotes below illustrate.

> "but I didn't have to have a colostomy bag or anything you know cos they measured me up for one and yeah obviously the first movement after that was a bit sooner and a bit scary" (Cath, 48 year old female, patient, time 1)

> "they said I was lucky they could join it together and I didn't have to have one of these things so" (Fred, 73 year old male, participant, time 1)

> "I didn't have to have a bag, thank goodness, thank goodness" (Eve, 62 year old female, patient, time 1)

All the participants in this study had received some form of palliative chemotherapy[20] over the course of their illness. Chemotherapy was taken orally, given by intravenous drip at the hospital, or in most cases was a combination of the two. In general terms, treatment with chemotherapy was viewed as a positive thing, as participants found it encouraging that something was being done although most understood that the chemotherapy would not cure their disease. The quotes to follow from Faye and Kate illustrate this point.

> "But I kinda panicked when they stopped it{chemotherapy} because I'm saying that's getting me better you know?" (Faye, 55 year old female, patient, time 1)

> "You{Gordon} might almost have been enjoying going because it{chemotherapy} was advancing the treatment and suddenly there's not so it might be that you need a bit more attention afterwards" (Kate, female, wife and carer, time 1)

However, the uncertainty of a) whether there would be any treatment and b) whether it would work caused Fred's wife Jane much anxiety.

> "It left us in a sort of limbo, I prepared for us to start, I prepared for him to start his chemo again and then she says well when do you want to come, what do you want to do sort of thing?" (Jane, female, carer, time 1)

Participants described varying experiences of the chemotherapy treatment itself. Chris was,

> "neither up nor down" (Chris, 80 year old male, patient, time 1)

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[20] Palliative chemotherapy is generally used to control symptoms, prolong life and to provide a better quality of life (Simmonds, 2000). This is in contrast to adjuvant chemotherapy which is designed to cure.

but for Eve,

"the cure was worse than the cancer" (Eve, 62 year old female, patient, time 1)

The side-effects associated with chemotherapy treatment included fatigue, numbness of the hands and feet, nausea, diarrhoea and hair loss - which was the most commonly discussed. Eve expected to lose her hair but did not, despite preparing for it by cutting her hair short.

"in anticipation of having a bald head I went and got a very, very short haircut and then half way through the treatment she…and you're not having the treatment where your hair falls out, thanks a lot" (Eve, 62 year old female, patient, time 1)

Unlike Eve, John did lose his hair. John's hair loss made his illness visible, which he worried caused people to shy away from him.

"I admit some people when the hair was you know and they look at you and I say it's alright it's just chemo haircut and as far I'm concerned some people sort of shy away a wee bit" (John, 62 year old male, patient, time 1)

Ann spoke hypothetically about losing her hair and although it had not happened at T1 she remained fearful about it,

"Although you know, I was prepared for it and I just thought…, em but I am not going into the world bald. You know, I know people do it and good on them but eh it's just not how I see myself" (Ann, 67 year old female, patient, time 1)

Generally participants were stoic about the treatment as they reasoned that it was helping them even though they may have at times may felt otherwise.

"The way I look at it it's keeping me here. I'm here eh" (Brenda, 60 year old female, patient, time 1)

Furthermore some could see tangible results which they considered encouraging.

"I'm consoling myself with the thought that the chemo has shrunk something because it's no longer pressing on something else, whatever was causing pain so that's one step in the right direction" (Deirdre, 66 year old female, patient, time 1)

"I'm just aware that they're doing the best that they possibly can and it's obviously working, whatever they're doing. Sick as it may make me" (Eve, 62 year old female, patient, time 1)

6.2.1.3 Coping strategies

6.2.1.3.1 The 'ups and downs'

Participants described changes in their mood which they often referred to as 'ups and downs'. This alternating pattern of emotions was viewed by the participants as characteristic of the experience of being diagnosed with a serious illness. Further exploration revealed the strategies that participants had devised to cope with the downs. For Eve this involved acknowledging it, realising that it was a normal response, and accepting it.

> "I've learned how to sort of recognise them and it's not that I, I don't say oh I mustn't think that way you know or pick yourself up and get on with it bla, bla because I think there are times when it's okay to say I'm having a rotten day" (Eve, 62 year old female, patient, time 1)

John's strategy was physical in comparison to Eve's emotional strategy, and he preferred to go out of the house and busy himself.

> "How do I cope with the bad days? Go out, go walking round the block just get out in the fresh air I find what's quite good when it's bad days if it's raining I walk out in the rain" (John, 62 year old male, patient, time 1)

There were more specific ways of coping that participants employed. For example, humour was seen as an alternative feeling depressed or sad by Deirdre, Eve and Faye. Humour was an important aspect of everyday life for these female participants so it was not surprising that it was used throughout the interviews. Both Deirdre and Eve made several jokes throughout the interview and used black humour as a way to lighten the sensitive subject of the interview.

> "Oh dear that's a laugh sometimes you know you have to laugh or you would be down in the dumps all the time" (Deirdre, 66 year old female, patient, time 1)

> "I mean a lot of it it's laced with humour it's sort of dark humour but I mean if you didn't laugh you would cry" (Eve, 62 year old female, patient, time 1)

6.2.1.3.2 Parameters of illness/wellness

All participants attended the clinic at regular intervals, although the intervals varied according to the severity and stage of their disease. At the time of the first interview

these intervals ranged from six weeks to three months. At the clinic, participants had their weight measured and a blood sample taken, which was used to assess the progress of the disease – this was later interpreted by the oncologist and the results reported back to the patient within two weeks of the sample being taken. However, participants also developed their own parameters of illness and wellness as a way of coping with uncertainty during the interim period to subjectively measure their own progress.

Weight was the most common measurement that participants used to evaluate the progression of the cancer and their overall illness or wellness. Weight was easy to measure and was noticed by other people and thus it was a tangible indicator of their progress. This quote from Gordon illustrates how weight gain was a gauge of his recovery after his surgery.

> "Well I was out of hospital within 9 days I mean I put all the weight back on" (Gordon, 65 year old male, patient, time 1)

Deirdre was concerned that she was losing weight but put it down to diet rather than the progression of the illness.

> "that basically is why I'm losing weight I think because I'm not eating properly I try to have a reasonable balanced diet" (Deirdre, 66 year old female, patient, time 1)

Pain was seen as another parameter of increasing illness or wellness. Participants expected to be in pain so found it reassuring that they were not suffering at the time. Faye and John both referred to pain in the quotes below.

> "I'm happy with myself because I havenae got any bleeding or anything like that. I suffer a wee bit of constipation erm but I'm no in pain" (Faye, 55 year old female, patient, time 1)

> "but I've not suffered any pain yet" (John, 62 year old male, patient, time 1)

6.2.1.4 Striving for normality

Participants expressed a need to act normally in spite of the cancer. This was not a means of denial or disavowal (as Cath confesses in the second quote below), rather it was their way of adapting to their different lives. Participants described different ways

of adapting to the new normal. Cath did not want to be seen as a victim of cancer so she went to work, went swimming, walked the dog and socialised with friends in the same way she had done prior to the diagnosis.

> "I try to lead a normal life (yeah) you know I don't like to be perceived as a cancer victim" (Cath, 48 year old female, patient, time 1)

> "I just cope by trying to act really normal you know and just try not to think about it although you know obviously about an hour or so doesn't go past where I don't think about it but I try and just, you know. I'm at work all day and my colleagues are great and my friends" (Cath, 48 year old female, patient, time 1)

Like Cath, Fred and his wife Jane described how Jane's continued employment gave them the chance to adapt to Fred's illness individually, without making any drastic changes to their lifestyle. Maintaining routine in their lives was important to Fred and Jane, as it gave them space to adapt to the illness.

> "Jane   You need that you need to be separated because there's no point in changing our lifestyle, that isn't going to help anyone. I could have stopped working there and then but we thought it wouldn't be a good thing
> Fred   Oh no, you're just as well
> Jane   Because you need time apart you both need time to adjust to things, you know we both need time" (Fred, 73 year old male, patient and Jane, female, wife and carer, time 1)

Like Jane, a number of the participants remained in paid employment which gave them a sense of purpose, in addition to improved financial security. For many, continuing in paid employment helped them to lead what they perceived as a 'normal' life. Participants described that it gave them the opportunity to interact with others who did not necessarily know about their illness. Duncan's work gave him a sense of purpose, as the first quote illustrates, yet it also tired him out meaning that he had the opportunity to temporarily cease thinking about his illness. This was a welcome break from speculating about his future which otherwise consumed his thoughts, as the second quote highlights.

> "I mean I like getting people {at work} who've got a good sense of humour. Ken, I like to leave them with a smile on their face and that" (Duncan, 57 year old male, patient, time 1)

> "I just work as many hours as I can to keep me busy then I go home tired then I go to bed and sleep cos I was going to bed and I couldnae sleep. Now I'm going to bed and I'm tired and I can sleep and get up in the morning and go back and get a shower and I'm back out" (Duncan, 57 year old male, patient, time 1)

Behaving 'normally' made participants feel more in control of their illness; was considered to be a way of coping; and, as the quote to follow from Andrew suggests, it was seen as another parameter of wellness.

> "I mean as long as I can work and be involved with everything with ma family and everything that's goin on then you've got to be positive in that respect" (Andrew, 57 year old male, patient, time 1)

6.2.1.4.1 The challenge of engaging in the social world

There were challenges in attempting to normalise. People gave examples of the things that gave them a sense of 'being' in the social world. Some described socialising with friends, whilst others reflected on the activities that brought them happiness and a sense of achievement, such as exercising, painting or playing guitar. Some participants highlighted that they needed to engage with people in order to feel normal again but there were challenges to doing this. For example, social engagement was occurring in the context of changing relationships. Participants worried that disclosing the diagnosis to their friends and family would affect their interpersonal relations.

There were physical and emotional challenges associated with most of the social activities. Those who continued to work described being excessively tired, and for some there were challenges in taking time off for chemotherapy and clinic appointments. Eve had to give up teaching the guitar as she could no longer play due to the numbness she experienced in her hands which resulted after the chemotherapy. This had been a job which she very much enjoyed for the artistic and social aspects alike. Likewise, Andrew regretfully described having to give up a hobby which he had enjoyed for decades, as he could no longer stand outside in the cold for prolonged periods of time.

> "I've given up a lot of things in the respect that I [community involvement] for about 27 years, different age groups but I still go and watch it but I dinnae want to be involved as much as I used to be to be totally honest" (Andrew, 57 year old male, patient, time 1)

Although Edward was still able to get out in spite of the increasing tiredness and worsening diarrhoea, at the time of the first interview he was finding it difficult, "messy and yuck."

Emma   Does the diarrhoea stop you getting out and things like that?

Edward   No it just means I know where the toilets are (Edward, 74 year old male, patient, time 1)

Deirdre described that it was difficult to make plans which made socialising more difficult. However, she was happy to be open and honest with her friends about the situation and her reasons behind her irregular attendance at lunches, as the quote below illustrates.

> "I said look this is it, it's palliative this time I said if I feel good I'll come I said I'll maybe not stay long but I'll come and try and put in an appearance so I managed I was fine" (Deirdre, 66 year old female, patient, time 1)

In terms of the emotional challenges, Brenda confessed that although she felt supported by her family and friends, nobody could fully understand how she was feeling which put a strain on her personal relationships.

Many of the participants in this study were acclimatised to the experience of cancer because they had seen relatives and/or friends go through it. This made participants reflect on their own experiences; past and present, good and bad, which shaped how they viewed cancer and the care they received. Moreover it highlighted some of the societal attitudes towards cancer. Participants were witness to, and felt the effects of such societal preconceptions. For example John felt marginalised, as I quoted above when he lost his hair and was forced to disclose the diagnosis. Likewise, Kate was surprised that some of their friends had reduced contact with her and Gordon after they heard the diagnosis meaning she felt marginalised from her group.

> "Some people that you think might be erm always asking and they're nowhere near you, you know. I don't know whether it's just embarrassing to ask or they don't want to bother you" (Kate, female, wife and carer, time 1)

6.2.1.5 The meaning of time

Several participants alluded to being constrained by their prognosis and thus the time they had left became important and meaningful. Additionally, the way the narratives were told conveyed how the construct of time changed throughout the course of their

experience. For example terms such as 'whipped in' and 'plunged' were used to illustrate the sense of urgency about their treatment; suggesting a slightly chaotic story. For others there was a delayed diagnosis, with several visits to their GP before finally being referred to the hospital. Often these participants could remember the day and dates of these encounters with great clarity, so were able to illustrate the slow pace of their stories.

Many participants described how time slowed when they were waiting for the diagnosis, operation or treatment. Waiting long periods of time was detrimental for participants, and some questioned how this time had influenced the progression of disease. For example, in the quote below Kate reflects on the time her husband had to wait until he was given a diagnosis. Kate wondered if the delay in being diagnosed resulted in the spread of the disease. Note the repeated use of the phrase 'three weeks' in the first quote which emphasises the length.

> "It's the waiting that's it. The waiting the three weeks, three weeks, three weeks and just they just didn't seem to care and they just didn't seem to think, how an earth is somebody going to feel when they're getting put off for another three weeks" (Kate, female, wife and carer, time 1)

> "how much has that all gone towards it spreading into the lymph nodes, I mean that 3 and half months" (Kate, female, wife and carer, time 1)

6.2.1.5.1 Uncertainty

During the interviews I usually asked participants if they thought about the future. In most cases the topic was raised with minimal, if any prompting from myself. Feelings of uncertainty dominated participants' thoughts about the future. They were uncertain about their prognosis – how long might they have left and how the illness would progress. The quote from Andrew, in response to being asked if he ever feels down or blue illustrates this.

> "I mean there's certain days when you're saying to yourself em if you're, when you're sittin on your own and you're saying ken what's gonnae happen?" (Andrew, 57 year old male, patient, time 1)

Likewise Eve was thoughtful about the time she had left and she was unsure if she would still be alive for her daughter's wedding,

> "she was saying we'll bring the wedding forward if you'd like and I thought no it's alright" (Eve, 62 year old female, time 1)

However there was also uncertainty about how the illness would progress, as Duncan mentions in the quote below. Note how Duncan was worried that he might self-generate symptoms if he thought too much about it.

> "I've never looked at the symptoms of ma cancer and how it will affect me but erm but I'm sortae scared to go that route in as much as well I might have certain symptoms and I might self-generate symptoms (uhuh) oh I've got a wee ache here and I'll make things worse. Pre-empt symptoms" (Duncan, 57 year old male, patient, time 1)

In the context of such uncertainty, participants discussed death in both direct and indirect ways at the first interview. Several participants described how friends or relatives had died of cancer thus introducing death to the narrative in an indirect way. For example, Faye used sub-narratives about the deaths of her husband, mother and niece to express her fears about her death and how the family would cope in an indirect and non-threatening way.

Others were more direct, yet still speculative about their wishes for the future, as the quotes below illustrate. For example Ann 'would not' want to be alone, and Duncan did not want to see people that were only there because he was dying and Eve did not want to be incapacitated.

> "I wouldn't want to be on my own because I think, I mean I'm not a very introspective person or introverted as you can tell. I might be introspective but I'm not very introverted. Em, I think that I would probably brood a lot more" (Ann, 67 year old female, patient, time 1)

> "I didnae want to see people that I haven't seen for months on end suddenly appear at the bottom of my bed" (Duncan, 57 year old male, patient, time 1)

> "I'm going to make something that says bury me or kill me or do, I don't want to be a vegetable" (Eve, 62 year old female, patient, time 1)

6.2.1.5.2 Seeking meaning in the past

A number of the participants described seeking meaning in their past, in response to the incurable diagnosis they had been given. They attempted to link experiences in their past to their present. They explored the beliefs which shaped their individual experience and the way they coped with the cancer diagnosis. Not only was this a potentially therapeutic behaviour for the participants but it helped me to contextualise their story. Two of the male participants described how they came to understand and get a sense of where they had come from. Duncan told me about the main events which he considered turning points in his life and which he thought shaped the man he was. As he says in the quote below, he was piecing himself together.

> "it was just again piecing myself, just piecing together how, what makes me what I am?" (Duncan, 57 year old male, patient, time 1)

John, the second participant, described a keen interest in exploring his genealogy which gave him a greater sense of where he came from.

> "I discovered a distant relative through the family tree and I arranged to meet with her, her and I are about the same age actually and she had information that I didn't have and I had information that she didn't have." (John, 62 year old male, patient, time 1)

Moreover I gained insight into the participants' belief systems and the things that were important to them. People reflected upon the things they had achieved and major events in their lives and gave examples of things that were meaningful to them. For example Edward and Iris talked of their travels,

> "Edward   We did it while we were able to
> Iris   It's just as well, when we your age we didn't have the opportunities to do it so you had to start when you sort of retired and eh fortunately we've done a fair bit" (Edward, 74 year old male, patient, and Iris, female, wife and carer, time 1)

Others reflected on major events that had occurred and that they felt had shaped their lives. For Lily and Harry this was the death of their son.

> "And that's my son who died. Five year ago. Marriage broke up, took to the drink and ……..I think it would have been worse if he'd been near but it was hard but you just have to get on with it" (Lily, female, wife and carer, time 1)

Similarly Faye described when her niece died,

"it was years ago when I lost ma wee niece, she was only 18 months and I had a lot to do with her then and she was like ma own" (Faye, 55 year old female, time 1)

The stories of Harry and Lily, and Faye illustrate how they introduced death into the overall narrative in a non-direct way – a sign to me that they were thinking about it but not yet ready to discuss their own death.

6.2.1.6 Health Professionals – role and relationship

The participants generally saw themselves as passive recipients of care; particularly in the early months after the diagnosis, although most became more active in terms of decision making as the illness progressed. In the early stages of the illness, most participants preferred to be told what the best course of action was. In fact one patient was shocked when he and his wife were asked to make a decision about treatment. Neither Fred nor his wife Jane wanted the responsibility of making such a decision; particularly one which could affect his life so dramatically.

"Usually the doctors tell you what to do, you don't tell them what to do" (Fred, 73 year old male, patient, time 1)

Moreover Deirdre thought she had a responsibility to co-operate with the professionals.

"I feel that if you can't take what the doctor's saying and co-operate then what's the point, there's no point in going to the doctors if you're not going to do what you're told" (Deirdre, 66 year old female, patient, time 1)

Participants seemed to implicitly trust the professionals on the basis of their experience and were happy to put themselves 'in their hands'. The quote below illustrates the trust that was felt towards the health professionals.

"I'll place myself in their hands, they're the experts. Do what they want when they want" (Duncan, 57 year old male, patient, time 1)

The quote below from Brian suggests how there was an implicit trust because professionals were very experienced.

"they have the experience of people with this complaint shall we say or eh, with cancer. So they know exactly what you're, maybe not 100%, 99.99% well they don't have it theirself but they can sympathise. They know what you're going through." (Brian, 59 year old male, patient, time 1)

Participants felt that the professionals should be sympathetic, yet encouraging and be good at listening.

6.2.1.6.1 Communication

Participants described occasions when they felt they were not being listened to by professionals. For example, some participants had a hunch that something was wrong with them when they first started feeling ill but when they informed the professional of this they were denied a voice. The quotes to follow from Lily, and Gordon's wife Kate illustrate this.

> "He tried to tell our doctor eh he felt as if what he was eating wasn't going down so there was something there but nobody would listen to him" (Lily, female, wife and carer, time 1)

> "It's not as if he's been backwards and forward to the doctor like a yo-yo….If he's complaining about being ill and he's got a problem, they should really head for the big ones straight away" (Kate, female, wife and carer, time 1)

Others felt alone as they did not know who to contact in the event that they needed information.

> "sometimes I think I wouldn't know who to phone really so roughly I don't really want to bother my oncologist cos she's busy and stuff but I do. They have given me names of the nurses that I could phone up" (Cath, 48 year old female, patient, time 1)

> "he explained what would have to happen, there was a nurse brought in and introduced to us and she would be there for us if I wanted to phone for help at any time and she would be there when he went into hospital and she would see him in hospital and she would be on hand. We never, ever saw her….it all sounded so nice that there was somebody there to help you and guide you" (Iris, female, wife and carer, time 1)

6.2.1.7 Summary – The first interview

The diagnosis story was the starting point for all the participants at the first interview and represented the beginning of the participants' cancer journey. Although different storytelling styles were evident there were key aspects in each of the stories. Participants shared their emotional response to the diagnosis and their experiences of treatment in terms of both surgery and chemotherapy. They expanded upon their coping strategies; how the dealt with the 'up and downs' and how they adapted to having cancer. There

were physical and social challenges associated with this adaption; for example, a number of participants were still in paid employment at the time of their recruitment, therefore accommodating the treatment regimen and the associated side effects presented a challenge. Likewise, socialising became difficult and participants worried that they were viewed differently by their friends and family, which made adapting to the cancer even more difficult.

All the participants had been told that their cancer was incurable, and in light of this the meaning of time had changed. They spoke about the past and the time they had left. Feelings of uncertainty were evident with regard to how long they had left to live but there was also uncertainty about how the illness would progress. Would they be incapacitated as Eve feared? Would they be in pain as John and Faye expected? This uncertainty made participants reflect on the meaning that their lives had had. Although participants were generally happy to be passive recipients of care, and relinquish control, they also wanted to feel supported and reassured by health professionals.

6.2.2 The second interview (T2)

The themes to follow emerged from the 14 interviews that were carried out at T2. I conducted 13 patient interviews (nine individual patient interviews; four joint patient and carer interviews) and one individual carer interview. Although this was only the second time I had met with the participants face to face I had spoken monthly with the participants in the variable group by telephone. My reflections on the telephone calls are discussed in chapter eight of this thesis.

6.2.2.1 The cancer story (The Middle)

All but one female participant commenced the second interview with what I have entitled, the cancer story. The cancer narratives about change and transition replaced the diagnosis story which was told at the beginning of the T1 interviews; however it was

less well defined than the diagnosis story. On the whole the cancer story set the scene for the interviews and they guided me in making decisions about where to probe further. During the cancer story participants reported changes in their physical condition, if/how the cancer had progressed and what treatment they were receiving. The cancer narratives were the obvious place for participants to start when we met for the second time - as the diagnosis story was when we met for the first interview. The stories were well rehearsed by participants and it was clear that they were recited often, to health professionals, family and friends. Thus, the cancer story and the diagnosis story reflected a public account of their illness.

Participants generally told their story as a sequence of events, but some focused on the more immediate aspects of their illness. For example, I heard about their last visit to the clinic or GP, their last session of treatment with chemotherapy, or their last scan. However, eight of the 14 participants who were interviewed described what I have termed a critical event. Such critical events included; a deterioration in their condition (often that the disease had further metastasised); a change of treatment, perhaps to a more aggressive chemotherapy; or in some cases chemotherapy was stopped if it was no longer working. Some of the critical events that were described were not directly attributable to the cancer. For example, Chris had incurred a blackout at home which resulted in a hospital stay. Like Chris, Ann had incurred a long stay in hospital hence the T2 interview was at month ten of the study as opposed to month six. Participants described episodes of pain more frequently at T2 when compared with T1. This quote from Deirdre highlights a number these so-called critical events. She had been diagnosed with further metastases in her head and was in pain as a result.

"So then I had... it's manifested itself at the back of my head, 'metastases' I think it's called. And it was sore, it was really, really sore" (Deirdre, 66 year old female, patient, time 2)

Faye did not commence her second interview by telling me the cancer narrative which is in contrast to the other participants. Instead she opened the interview by telling me that

she now felt she had a death sentence when she had not before.   The extract below from the very beginning of interview two illustrates this.

> "I actually feel now – and I never felt it before – I've got a death-sentence now (right). Aye, that is how I feel now, erm… But I don't feel… I do feel like that but I don't… not all the time" (Faye, 55 year old female, patient, time 2)

Faye spoke more openly about potentially sensitive issues from the outset of the interview which is in contrast to others who eased themselves into the interview by firstly narrating the well rehearsed cancer story. Faye's ability to reflect more widely on her situation could be the result of the regular contact we had by telephone, an issue which I will discuss in detail in chapter eight. At T2 Faye demonstrated her ability to be reflective about the changes that had occurred since the T1 interview suggesting that just as I had reflected on what to ask Faye at the subsequent interview, she too had been thinking about it.

6.2.2.1.1 Changing physical appearance

For a number of participants, the progression of the cancer was associated with changes in the participants' physical appearance. For example, requiring stronger chemotherapy meant that they were more likely to lose their hair. Some gained weight as they required steroids to stimulate their appetites and others lost weight because they were no longer able to eat a normal diet, or as the disease became more severe.

In the same way that participants devised and interpreted their own parameters of illness and wellness at T1, some participants attempted to interpret changes within a positive framework. This allowed them to feel like they were regaining confidence in their bodies after the diagnosis. For example, Brian found it encouraging that he had not lost any weight since the last interview as this quote highlights.

> "I know that I'd be losing weight if there was something serious going on" (Brian, 59 year old male, patient, time 2)

In contrast to Brian, other participants like Faye interpreted any change as circumspect, and a sign that the cancer may have returned.

> "I'm saying to myself "I know that I'm not feeling great, is this my body telling me that the cancer's back?" (Faye, 55 year old female, patient, time 2)

However, the participants' relationship with their body differed from how they described it at T1. In many cases the participants were sicker, and the signs of this were objective, rather than subjective as they had been at T1.

6.2.2.1.2 Not a victim

Participants did not want to be perceived (nor see themselves) as victims of cancer. Ian strived to keep his reputation as the motivated, sociable and physically strong man he was well known as, not as a victim of cancer. He had overcome the challenges and stigma of being diagnosed with Parkinson's disease at a young age and approached the diagnosis of cancer in the same way. Instead of retreating, Ian continued to socialise and attend events with those people whose perception of him was so important. Similarly Duncan wanted to be seen, and remembered as the jovial character who liked a laugh, not the victim of cancer. Duncan also expressed that he was uncomfortable talking about his condition when people asked him about it. He wanted to be seen as upbeat, and that in spite of his situation he was making the most out of life, as the quote below illustrates.

> "everybody asks me, I never ever broach the subject of it or ken, "I've been to the hospital today." People say "what's happening?" and I always try and get off the subject as quick as possible" (Duncan, 57 year old male, patient, time 2)

Andrew wanted to be seen in the same way as he had always been by his friends and family yet he worried that people would shy away from him when they heard about the cancer, as the quote to follow illustrates. He did not want to disrupt his existing relationships or potentially thwart the formation of new ones by disclosing the diagnosis.

> "Well I think sometimes when people look at you I think, and I'll maybe be wrong here but sometimes when people know that you've sort of got cancer there sort of I don't know if they avoid you or they stand back" (Andrew, 57 year old male, patient, time 2)

Moreover Andrew did not feel, nor considered that he looked ill. In fact he still described himself as a 'fraud', as he had at interview 1. In spite of his overall reluctance to disclose the diagnosis, this quote illustrates how he wanted to assure me that he was not hiding his illness and in so doing assured me (and his sister Gill) that he was not denying he was ill.

> "I keep on telling that to the doctor when I go in and see her I feel a bit of a fraud here because I dinnae feel ill and I know I am so I'm not, I'm not hiding the fact that I'm ill but I don't feel ill, eh (Andrew, 57 year old male, patient, time 2)

6.2.2.1.3 Maintaining a positive outlook

Many of the participants alluded to the importance of maintaining a positive outlook. Some took what they saw as the positive aspects of their illness experience to fuel their positive outlook. For example, John saw that he had survived 18 months, in addition to the time he was unaware of the cancer, which he considered a positive sign.

> "I mean, I've survived 18 months *(mm)* plus, because *(yeah)* there's the time before when I had the cancer and I didn't know about it *(yeah exactly, and you didn't know)*. So I mean, I'm 18 months down the line and I didn't think I'd be 18 months down the line to be honest with you. I mean, when somebody tells you you've got cancer you think "oh shit" you know – excuse my French!" (John, 62 year old male, patient, time 2)

Likewise, Gordon was encouraged that in the past he had been given good news at the clinic, so he expected it again.

> "When I go alone I don't expect to get bad news but when you hear the good news it's always good to hear from the consultant himself. It's nice when he tells you that" (Gordon, 65 year old male, patient, time 2)

It is noteworthy that neither John, nor Gordon were in denial about the severity of their illness, which illustrates a dual narrative. John was hopeful about surviving as his mother had done but he knew that his condition was incurable. Likewise, Gordon knew that it was possible that he could get bad news at the clinic.

Participants worked, socialised and generally kept themselves busy which helped them to focus on the positive, and temporarily cease thinking about their situation. For example, Cath kept herself busy by meeting with her friends and family and with two

teenage children she had a household to run in addition to a job, which kept her from ruminating on the cancer during the daytime hours.

> "I've been fairly positive most of the way and I'll just try to keep that way. Try and keep myself busy so yeah so. There's not much I can do about it so erm I just try and keep positive" (Cath, 48 year old female, patient, time 2)

Like Cath, both Duncan and Ian felt that keeping busy and active was key to maintaining a positive attitude rather than dwelling on the negative, as the quotes below illustrate.

> "I think it's just not worth thinking about it too much, just keep yourself active, no sitting dwelling on it, no thinking about it too much. And if you keep active, keep positive, you know, if you keep active that in a sense keeps you positive" (Duncan, 57 year old male, patient, time 2)

> "I'm keeping active keeping the mind going so I'm no depressed or anything" (Ian, 65 year old male, patient, time 2)

Both Andrew and Chris highlighted the role of treatment in maintaining positivity. Treatment played a vital role for participants as it enabled them to feel that they were being actively cared for, as opposed to feeling abandoned. For most, in spite of their terminal diagnosis, chemotherapy/radiotherapy or surgical treatment gave participants hope as the quote from Andrew illustrates.

> "the doctor said there would be other drugs if it was necessary we could use them as well. But the chemo itself seems to be shrinking it" (Andrew, 57 year old male, patient, time 2)

As the quotes to follow suggest, the positive outlook was by no means easy to maintain. To all participants, patients and carers alike the cancer was omnipresent. Brian and Deirdre recognised that despite their best efforts to restrict the thoughts of cancer but it was always present.

> "I mean you can't keep doing something to keep you occupied and keep your mind off it because you go back to it immediately" (Brian, 59 year old male, patient, time 2)

> "I try not to think about it anymore than I can help. I mean, it's generally in my bed at night and my brain starts whirling, sometimes in the morning as well when I wake up" (Deirdre, 66 year old female, patient, time 2)

Faye, like Brian and Deirdre thought that although she should have a positive outlook, it was not always easy as the cancer was 'nagging at the back of your head'.

"I think that's where, when they all go away, you can come down because you're being so positive. But there's also that nagging at the back of your head that it's not." (Faye, 55 year old female, patient, time 2)

6.2.2.1.4 The 'fight'

Participants described the need to 'fight' the cancer, and staying positive was just one weapon they employed. The thought of what would be left behind them in terms of a legacy was another driving force in their fight. For example, Duncan acknowledged that although he experienced bad days he still had to 'battle through' and be seen as doing so for the benefit of his sons. However in the quote below Duncan speaks in the third person, suggesting that perhaps battling the cancer was something he felt he should be doing rather than something he was able to do. I discuss this idea of the moral imperative in chapter seven of this thesis. Duncan feared letting his sons down by giving up, but by battling the cancer he would leave behind a positive emotional legacy.

"you get a wee bit emotional at times but other times you just sort of… you've just got to battle through it, you know" (Duncan, 57 year old male, patient, time 2)

The quote below from Len, Brenda's husband highlights how Brenda's fighting spirit gave Len hope. At T2 Brenda was ill in hospital so I met with Len for an interview in the family home. Len coped with Brenda's worsening condition by being hopeful that she might improve as she had done before. This is what Duncan wanted to achieve for his sons.

"And she is a fighter and she's had surprises before" (Len, husband and carer, time 2)

Ian was committed to the fight and was hopeful that his active stance against the cancer, by adopting a healthy diet and exercise would allow him to overcome the doctor's prognosis.

"I don't think I will get old. I'll pop it in a couple of years like Dr said but I hope no. I'll fight it." Ian, 65 year old male, patient, time 2)

6.2.2.1.5 Acceptance

In contrast to T1, some participants voiced that they had accepted the terminal diagnosis of cancer. Although this first quote from Faye seems in itself contradictory, it echoes

what was seen in a number of the transcripts - that often people remain hopeful until the end.

> "I've accepted it, aye. I'm not, erm… I don't get myself upset and all that about it because we can all be wrong" (Faye, 55 year old female, patient, time 2)

Having said this, Harry and Lily showed little evidence of feeling hopeful and felt that the only thing left was to accept it.

> "we'll just have to accept it, more or less, there's not much you can do about it." (Lily, female, wife and carer, time 2)

Furthermore Gill spoke in her role as the main informal carer and next of kin to her brother Andrew. The quote below suggests that she also felt that she had to accept the diagnosis, as she uses the pronoun 'we'.

> "we've accepted the fact that yeah that it's there and it won't go away em and I think that's the hardest hurdle is acceptance of that don't dwell on it, try and get on wie your life as best you can round about it" (Gill, female, sister and carer, time 2)

6.2.2.2 What legacy?

Participants considered what legacy they were leaving behind them when they died. I introduced this earlier in this chapter when I spoke of Duncan's need to stay positive for his sons. Predominantly males spoke of the material legacy which they wanted to leave and thus they highlighted the practical tasks which they had already carried out to secure the financial future of their loved ones. However, there was also the legacy about how they wished to be remembered. As I mentioned in the section 6.2.2.1.2 (page 139), Ian wanted to be remembered as the strong, motivated man and Duncan as the light-hearted, fun man. Neither Ian, nor Duncan wanted to be remembered as a victim of cancer. Duncan wanted to be remembered fondly by people which is evidenced by him telling stories about the good deeds he had done, and the pleasure he felt he had had given to others. He wanted to be perceived in this way by the people he knew but also by me in my role as the researcher hence telling me these stories. The quote to follow was told in the context of how he wanted his sons to remember him.

"I mean, the most important thing is for people to turn around when it's your time to move on and they say "well, your dad was a gentleman, he did this, he did that" (Duncan, 57 year old male, patient, time 2)

Similarly Ian, whose career meant he was somewhat of a local celebrity, told me stories illustrating what people thought of him.

"The best bit of the lot was when I was in the gymnasium, did I tell you about that? And I goes through the [sporting event] where 26 are [sporting] away and everything and I shouted to [friend], I'll see you on Thursday, having a cup of tea and a blether, I says I'll see you on Thursday and [they all] turned round and says I'll see you on Thursday Ian. You cannae buy that." (Ian, 65 year old male, patient, time 2)

Both Duncan and Ian wanted to feel that they had a meaningful life and that they were leaving something memorable behind them when they died.

Two female participants shared their concerns that their illness and death would leave a negative emotional legacy with their families. Following a significant deterioration in her condition, Deirdre was prompted to think about who should make the decisions about her future care. Deirdre described that she did not want her family to live with the decisions that had to be made - particularly those about her death - so she told the doctor that the responsibility of making decisions would be hers. This was not about her feeling autonomous, rather it was about the potential destruction to her family of living with the consequences of the decisions they made.

"I says "I don't want [husband] or [daughter] and [son] to have to make the decision to pull my plug. I'm saying now that if it's a no-go thing, then just do it. Sorry" (Deirdre, 66 year old female, patient, time 2)

Similarly, Faye expressed concern about her family looking after her at home. Faye had experience of caring for several family members, allowing them to die at home so understood the challenges. Faye was striving to protect her family from harm and leave them free from resentment. When talking about how she would be cared for when she got sicker she said,

"And we were talking about that, my sister [sister] and I, I says "well, to be honest, I'm not wanting that for anybody" I says "I'd just go into the hospital" (Faye, 55 year old female, patient, time 2)

And later in the interview,

> "I'm really not wanting that kind of friction in my own family" (Faye, 55 year old female, patient, time 2)

6.2.2.3 Certainty and uncertainty about the future

Akin to the findings at T1, participants' thoughts of the future were veiled by feelings of uncertainty. Note the way Eve uses 'I think' and 'probably' in the quotes below which alerted me to the uncertainty that she felt characterised her situation. In the quotes below, Eve is talking about her upcoming visit to the hospice where she would be introduced to the staff and get acquainted with the surroundings.

> "I think I'm going to get the sort of grand tour of the, it sounds a wee bit like the last resort but I think it's probably do me the world of good and they'll get to know me and I'll get to know them."
> (Eve, 62 year old female, patient, time 2)

> "I mean me and them, just getting to know them and sort of I think that's where I'll end up probably" (Eve, 62 year old female, patient, time 2)

Although there was the certainty of death, there was uncertainty about how the illness would progress and what the subsequent disruption to the quality of their lives would be. This quote below from my second, and last interview with John highlights the uncertainty he felt about the amount of time he had left.

> "obviously when you suddenly discover that you've got a sort of restricted timescale, you know, albeit you don't know what it is you know it's there" (John, 62 year old patient, time 2)

Ann's concern about the uncertainty of her future was evident, particularly when she contemplated that she may live a while longer with the poor quality of life she was experiencing at T2[21]. The quote below suggests that Ann would rather die than have to live in the predicament she was in at T2.

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[21] A summary of Ann's case study is presented in chapter seven (page 177), but in short; Ann had received extensive bowel surgery between T1 and T2 which meant that after a prolonged stay in hospital Ann was unable to leave her house for fear that her abdominal wounds would open and the contents of her bowel would leak out.

"They can't operate on me because my bowel is in such bad condition so they've got to wait for this to heal. And what if it doesn't? I mean I don't want to live like this for the rest of my life Emma. I mean I'll do away with myself. I MEAN it. I could not live like this forever" (Ann, 67 year old female, patient, time 2)

Participants not only described the physical changes they had experienced, but also reported changes in their attitude towards the illness. As Duncan suggests, the uncertainty of his illness focused his mind which Kate, Gordon's wife concurred with. Both participants referred to making the most of each day which echoed the thoughts of most of the group.

"So what it does, it focuses your mind: appreciate things, get everything sorted out financially, whatever else so that there's no hassle when you do pass. And just… just enjoy each day more, enjoy each day. And always try and turn a negative into a positive" (Duncan, 57 year old male, patient, time 2)

"I have thought about the need to not waste any time, just live everyday as it comes. Just we seem to be hearing an awful lot of my friends who have been getting cancer and what have" (Kate, female, wife and carer, time 2)

6.2.2.4 Altered personal relationships

Participants gave examples of how personal relationships changed in the context of illness. Firstly, relationships changed as a result of the ill person's physical deterioration. The interviews at T1 highlighted that socialising and interacting with friends was described as giving participants a sense of 'being' in the world. Despite valuing their relationships highly, participants described how maintaining them became increasingly difficult as the illness progressed. For some, visiting friends was difficult due to the physical constraints they now had. For example, Harry and Lily commented that although they still tried to go out regularly they were unable to travel by themselves any further than the neighbouring village.

Ann expressed similar difficulties to Harry and Lily and reflected on how the cancer had negatively affected her personal relationships - a result of her increasing inability to socialise. In the quote to follow Ann describes how the physical restrictions she was experiencing left her unable to participate in the activities as she had once enjoyed.

Ann's situation was emphasised because her husband was still very active - an issue which I return to in chapter seven (page 177). The forced inactivity that Ann was subjected to, lowered her morale and over time altered her relationships with her husband and friends.

> "It is I mean I'm usually such an active person you know, ….you know swimming every day and out for wee runs in the car and a wee picnic somewhere you know" (Ann, 67 year old female, patient, time 2)

Ann lost the confidence to socialise for fear that her body would let her down, as the quote below illustrates.   Moreover Ann was unable to eat or drink due to the complications of surgery so was therefore unable to participate in the norms associated with many social situations.

> "You can understand how demoralising that is and how totally disgusted I am. I can't go and visit friends like that. Even though they would understand, well would they you know? (*Absolutely*) You know as a woman you know. You're feeling about yourself, you self esteem and so on and I don't want to go about looking like a toothless old crone you know" (Ann, 67 year old female, patient, time 2)

Secondly, participants reflected that their role within the household had changed and this required a re-negotiation of their personal relationships. This was the case for both male and female participants and was often aligned with gender stereotypes. For example, Ann struggled as her husband carried out what she considered to be the female jobs around the house, namely cooking and cleaning. Ann's feelings of self-worth were somewhat placated as he needed help with the cooking, as the quote below illustrates.

> "…so he's cooking properly now. I mean he could always rustle up something. So he brings it through and I tell him do this, do that. So he's done very well. That sounds really patronising" (Ann, 67 year old female, patient, time 2)

Similarly, Faye had been used to looking after her immediate children and her siblings so reluctantly accepted help from others. Faye worried that her role as matriarch was being comprised and was uncomfortable with the change. Deirdre described similar concerns to Faye in that she wanted to look after her children. Likewise, Eve wanted to ensure that her affairs were prepared in advance of her death, so that her only daughter

did not have to deal with it. Eve prepared the paperwork and even addressed and stamped the envelopes.

> "Made the will, signed it, gave her a copy of it and said that's it, whatever I've got which is nothing, 10% of nothing, erm so she's go that and she's got it away and you know it's proper and it's all legal and all the rest of it. I said it's just basic stuff you know and I said you know I'll make out a list cos when you've been a librarian or a library assistant you're a pain in the arse" (Eve, 62 year old female, patient, time 2)

The men also reflected on how their roles within the family had changed. For example, Chris did not like feeling that he was being told what to do by his daughter – although he admitted that she was trying her best.

> "Dad what's wrong with you? You just sit in that seat, the sergeant we call her behind her back. She's just trying her best" (Chris, 80 year old male, patient, time 2)

Chris was very protective over his wife and he was worried that he may not be there for her in the way he should be. In this way Chris was negotiating a new role.

Changing relationships were linked to some of the other themes that were presented above. For example, participants were affected by their changing physical appearance (6.2.2.1.1, page 138). Participants wanted to be perceived in a certain way – and as 6.2.2.1.2 (page 139) highlighted, this was not as a victim of cancer. For example, Andrew had lost his hair at T2 yet resisted telling his friends and acquaintances about the cancer; much to the annoyance of his sister Gill who felt she had to tell people on his behalf. If Andrew was treated differently by his friends it might compromise his ability to maintain a positive outlook.

Interestingly, not everyone described changes to their relationships. For example, John continued to see his friends in the same way he had done before, as the quote below highlights.

> "I've still got the same circle of friends, I'll go down to the club in the evenings when they're down there, you know" (John, 62 year old male, patient, time 2)

Similarly Ian continued to see his friends and participate with the same hobbies, in the same way he had been doing for years. Did John and Ian differ in some way? I explore

potential explanations for this when I explore the individual case studies over time in chapter seven (page 175).

Unlike some others, Duncan felt his relationships had changed in a positive way. Duncan commented on the intensification of his familial relationships, particularly with his siblings because he confided in them about his concerns. Duncan believed that his illness had helped him realise the importance of family. In the quote to follow he is paraphrasing his uncle,

> "And my [name of uncle] lay in his bed and he says "forget your big houses, it doesn't matter about houses, at the end of the day it's… – " ken, because he knew his days… he was only days to go, actually – "at the end of the day" he says "all you've got is your family" and it's true. (Duncan, 57 year old male, patient, time 2)

Chapter seven develops this discussion of how and why the participants' relationships changed.

6.2.2.5 Relationships with health professionals

Within the cancer story, which was situated at the beginning of the interview, participants reflected on their relationships with health professionals. Thereafter the participants' focused more on personal and bodily relations.

The VCRM narrative analysis (4.8.3, page 93) includes a reading for how participants saw themselves in their relationships. This highlighted that there was frequent use of the pronouns 'they' and 'we' when participants talked about the professionals. There were occasions when the use of 'we' suggested that participants were engaged in the decision making process. For example, Duncan referred to 'we' when he was describing the success of his last round of chemotherapy.

> "We're pleased with that" (Duncan, 57 year old male, patient, time 2)

Likewise Deirdre and Eve both use 'we' when referring to decisions about treatment which suggests that they too were engaged in, and value their role in the decision

making process. Deirdre in particular wanted to be actively involved in making decisions to ensure that her family was not responsible for the consequences of such actions, as I described above.

Two of the female participants sought to be the 'good patient'. Cath and Eve both highlighted the importance of participating in clinical trials which although it was seen as a utilitarian act they were also investing in their futures and giving themselves the best chance of survival.

> "It's very important that people should go forward and you know, this no point in saying what's this, what's that you're going to die come on lady get it for God's sake." (Eve, 62 year old female, patient, time 2)

Unlike those participants I have just mentioned, both Brian and Ian used 'they' when referring to their health professionals, which suggests that a passive, not active role in the relationship they had with the professionals. This quote from Brian, which illustrates his use of the pronoun 'they', also highlights a power imbalance and a hierarchical relationship with his health professionals.

> "I'll ask them when I go back. If they tell me there's nothing there then that's fine I'll ask them when I go back. If they tell me there's nothing there then that's fine" (Brian, 59 year old male, patient, time 2)

6.2.2.5.1 Reassurance

As was the case at T1, the professionals' ability to provide reassurance to participants, particularly as they became sicker was seen as key, as it was at T1. Reassurance was sometimes direct - for example Len was keen to keep Brenda at home for as long as possible but required reassurance from the GP that he was doing the right thing for his wife. Len was able to cope with the day to day requirements of caring for someone but he did need the support of the professionals around him, both the GP and district nurse services.

> "I had to get the doctor in a couple of times the next again week, more so for reassurance than anything else" (Len, male, husband and carer, time 2)

Reassurance was also tacit – for example Chris was reassured about his deteriorating condition because he felt that the doctor had control and seemed happy. Such tacit reassurance coincided with Chris gaining confidence, thereby allowing him to live as full a life as possible. Although his condition was deteriorating, Chris still valued going out with his friends so having the confidence to do so was vital to his quality of life

> "They're growing in my liver and in my left lung as well so but they seemed to have got control of it and eh she's quite happy with it. She seemed to be quite happy, she's a cheerful person" (Chris, 80 year old male, patient, time 2)

Participants who experienced continuity in their relationships with health professionals spoke more readily of feeling reassured. Participants valued this continuity of care as it meant they felt better supported and knew who to contact if they needed to.

Poor communication between community and hospital care professionals compromised the participants feeling reassured. Len expressed that communication between the hospital and GP was poor and moreover had not improved over the course of Brenda's illness.

> "But the communication's still not very good between the hospital and the doctors, not really" (Len, male, husband and carer, time 2)

Likewise Eve described feeling like the middle man between her GP and oncologist and as a result she lacked confidence in them.

> "I think they're having a vendetta between me and my doctor (GP) because she keeps saying, what did the clinic say is it all, let's try this one then" (Eve, 62 year old female, patient, time 2)

Lily described a more positive experience when talking about the MacMillan nurse. At the time of the study Harry and Lily were the only participants to have a designated community MacMillan nurse who acted as an advocate for them. Overall this was a positive experience.

> "And she comes in and then she'll say "oh, I'll have a word with [doctor] and see what she says" you know. So I mean, as I said, that day she was in and she said "I'm going to see about this, I'll see [doctor]" As I said, between the two of them, they got him in for a scan the next day" (Lily, wife and carer, time 2)

6.2.2.6 Summary – The second interview

Nearly all the participants commenced the second interview by telling me the cancer story – the middle of their overall cancer journey which replaced the diagnosis story at the beginning of the T1 interviews. This narrative included an update on the progression of the cancer, changes to their treatment and it usually ended with a synopsis of their situation at the time of the interview. For most, there had been deterioration in their condition which was often associated with a change to their physical appearance. This altered physical appearance meant that the cancer was more visible to others which meant that some participants battled with being a victim or a survivor of cancer. Akin to the findings at T1, participants described their coping strategies, and like the earlier findings there was a need to maintain a positive outlook. However some of the male participants expressed a desire to 'fight' the cancer, as much for the sake of their loved ones as themselves.

Participants expressed concern about what they were leaving behind in terms of a legacy. Some of the men told me about leaving a material legacy for their families in so much as they had written a will and organised their finances. Others were more concerned about the emotional legacy they might leave with their loved ones. Some participants saw themselves differently in terms of their personal relationships. In practical terms, socialising for many became increasingly difficult as they became sicker, yet concern about being perceived as a cancer victim was also evident.

6.2.3 The final interview (T3)

In comparison to the interviews at T1 and T2 many participants spoke of their death with more certainty. For these participants, this was the last chapter in their overall narrative. The themes to follow emerged from the seven patient interviews (four individual patient interviews; three joint patient and carer interviews) and three bereavement interviews.

6.2.3.1 Prognosis story (The End)

Some participants had a very clear prognosis story which was interwoven through their T3 interviews. Two participants, namely Faye and Chris had been given a terminal prognosis between interviews two and three and thus been told by their health professional that they were going to die. Chris did not have an idea of how long he had to live only saying it was 'when', as opposed to using the word 'if'. The quote below is the opening dialogue with Chris from the T3 interview. With this response, Chris instantly set the scene for the remainder of the interview.

> Emma   "So how have things been since...? I last saw you six months ago
> Chris   Yeah. Well, the whole thing's probably wrecked (right). It's now terminal *(right, OK)* so it's only 'when'." (Chris, 80 year old male, patient, time 3)

When I enquired further about his terminal prognosis, Chris said he just accepted it although the 'if' in the second sentence of the quote to follow is slightly contradictory.

> "I just accept it. If it's going to happen, it's going to happen." (Chris, 80 year old male, patient, time 3)

Chris knew that death was approaching but he was unsure of the time he had remaining, whereas Faye had been told just a few days prior to the interview that she would only survive another few weeks. Since our last interview (eight weeks earlier) Faye had been feeling increasingly ill, had developed jaundice, and as a result she had requested an appointment for the oncologist. Unfortunately a scan showed that the metastatic tumour on Faye's liver was untreatable with either radiotherapy or chemotherapy, and accordingly she was told that she probably only had weeks to live. In the quote to follow Faye describes how she received the diagnosis.

> Faye   "I went back the week after and I thought the worst-case scenario was I'd have to go on the chemo and they were telling me I've got a few weeks to live *(yeah)*. But that was the worst-case scenario *(yeah)* because I went "oh god, chemo, god…"
> Emma   Mm-hm. So that must have been a bit of a shock.
> Faye   It was but I just felt… I can't even tell you how I felt." (Faye, 55 year old female, patient, time 3)

Faye went on to describe how she felt after being told the prognosis. Note Faye's need to qualify that she always knew the consultant was talking about her, despite her feelings

of overseeing, rather than engaging with the situation. The 'I have' in the second quote below suggests that Faye also wanted me to know that she had accepted and was dealing with the inevitable.

> "I don't know where I went, it was like I was taking off of there and lifted to somewhere else *(mm-hm)*. It wasn't that I think he was talking about somebody else *(mm-hm)*, I knew he was talking to me" (Faye, 55 year old female, patient, time 3)

> "But I never thought it would ever come to that *(yeah)*. Now that it has come to that, I've learnt "oh my god, I HAVE accepted" (Faye, 55 year old female, patient, time 3)

Proxy prognosis and death stories were also heard during the bereavement interviews. The carers gave details of the death of their loved one and made reference to how they kept their identity alive in the days and months that followed. The stories from the carers added context to the overall narrative. For example, Lily, Harry's wife described how he was sent to the hospital nearby, so she could visit him every day but he had died quicker than had been expected. Harry had been a 'Legion man' and it was very much part of his life therefore Lily had arranged for the funeral to be held there. Excerpts from my interview with Lily can be found below.

> "we got him down there, which helped a lot but I don't know whether he just gave up in the end or… *(mm)* Because they didn't seem to expect him to die as quick" (Lily, female, wife and carer, time 3, bereavement interview)

> "And we had a tea in the Legion, he'd been a great Legion man" (Lily, female, wife and carer, time 3, bereavement interview)

Len, Brenda's husband described how he had watched Brenda slip away in the years preceding her death.

> "Mind, she was ill for nearly three years *(yeah, that is a long time)*, ken? Ken, I'm saying "a year", ken, you've got to be going back 18 months, she got a wee spell off for six months *(mm)* but really you've got to go back 18 months, it was just downhill all the way" (Len, male, husband and carer, time 3, bereavement interview)

> "But it's just, you know… basically you're just seeing somebody dying, running away in front of you *(yeah)* and that, that's it in its crudest terms, is what you're watching *(yeah)* and that's what I watched for two years and it's not nice" (Len, male, husband and carer, time 3, bereavement interview)

6.2.3.1.1 Physical deterioration

Physical deterioration was experienced by most participants, in varying degrees of severity. Ann had recently suffered a nasty fall which meant she had been admitted to hospital. She was suffering from back pain and consequently her mobility was challenged. The fall and its repercussions were Ann's main concern at the time of the interview, as opposed to the cancer. Similarly, Chris had experienced a fall which, despite being given a terminal prognosis between T2 and T3 was his grave concern. Chris's fall had happened in the shower which left him feeling like an embarrassed, old man. This compromised Chris's characteristically stoical attitude, which had driven him to stay healthy and fit. The fall meant that Chris was forced to use two walking sticks instead of one – a visible sign of his deterioration. Chris did not want to be seen as giving in, even though his prognosis was terminal. He wanted to be stoical till the end. Such critical events symbolised the participants' increasing weakness and dependency on others. A role that at the first interview would have been unthinkable for these fit, autonomous and socially mobile individuals. Similarly, Faye spoke speculatively about her fear of being in pain and, like Chris's experience of the fall symbolising his increasing dependency, pain to Faye signified the end, and moreover the need for help out with the family.

How do the participants and the interviews differ when there was no prognosis story or critical event? Gordon started the interview by assuring me that things were going well. He was feeling physically well and his positive outlook was evident throughout. His positive outlook enabled him to feel confident that the outcome of his appointment would be positive. The fact that he was living with the cancer and there had been no change in his condition, or indeed critical event, enabled him to look forward to his future with hope. When asked if he felt his cancer could be likened to a chronic illness he said,

> "I just feel I've got something lingering away inside me but it's not going to get any worse *(yeah)*" (Gordon, 65 year old male, patient, time 3)

Gordon retold his diagnosis story for the third time during the third interview which was, in part to emphasise his frustration but also, because unlike other participants who replaced the diagnosis story with stories relating to their critical events, Gordon felt he had no other story.

6.2.3.1.2 The meaning of 'home'

Several participants spoke about home, some with reference to staying there when they were dying and others feeling like they were in a place of familiarity and security. Home was seen as a sanctuary, perhaps because it was a place that for many was associated with happy memories. For example, both Faye and Chris were clear that they wanted to remain at home as long as possible and would ideally die at home providing that they were not too much of a burden on their families. Chris and his wife Hazel were concerned they did not want to be separated at the end of his life, after 54 years of marriage.

> "We just don't want to be apart, you know *(yeah, I understand that)*. We've been married 54 years" (Hazel, female, wife and carer, time 3)

When asked about going into the hospice, Chris said he wished to stay at home providing Hazel could cope.

> "If it's not going to be too much for Hazel, that's the only thing *(mm-hm)*. If it's going to be too much for her I'll just go into the hospital. But she's coping alright." (Chris, 80 year old male, patient, time 3)

On the other hand Faye was adamant that she did not want to go to the hospice, which represents a noticeable change from T2 when she feared putting too much pressure on her family by staying at home. Given her role as matriarch, Faye's home was her sanctuary and kingdom and there she felt in control; able to invite people in and ask people to leave when she wished.

> "I could go into the [hospice] and get pain relief and come back home *(mm-hm)* but if they can do that in a day in [hospice] they can do that in a day in here as well *(yeah)*, well, that's what I feel *(yeah)*. I'm not going into the [hospice]..........I want to be here." (Faye, 55 year old female, patient, time 3)

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Both Chris and Faye were in contact with, and felt supported by hospice outreach services making them feel more comfortable about remaining at home as long as possible. Chris had been seen by a hospice nurse and was reassured by her that he could contact the hospice at any time as he had no further appointments at the hospital as the quote below illustrates.

> Emma   "So how often do you go to the hospital now then?
> Chris   I've not got an appointment now so I won't be going back again as far as I can gather *(right, OK)*. If I want to go to the hospice I can go at any time *(right, OK)*. I mean, they made a point on that, they said "you can come in here at any time" *(right)* but I'd rather stay at home." (Chris, 80 year old male, patient, time 3)

In contrast to Chris, Faye had not actually seen the district nurses, the hospice nurses, nor her GP, but she assured me that when she was in pain she would utilise their services. According to Faye, the nurses and GP had a very specific role to play when the time came and that was to ensure she was not in pain.

> **"**I've got district nurses, [hospice] nurses, the GP *(right)*. They've never been *(OK)*, I don't need them, because I've always got… *(yeah)* and I'm not in any pain *(OK)*. I don't know when the pain sets in, if it's different medication that they will have to come in *(mm-hm)*, but so far" (Faye, 55 year old female, patient, time 3)

Len, Brenda's husband described having a very positive experience with the hospice when we met for a bereavement interview at T3. The quote below illustrates this.

> "I feel that they're such great people down there *(mm)* because they're seeing that day in, day out *(yeah)*. They know not every patient, or not every patient's friends or relations, will face up to the fact that they're dying *(mm-hm)*. There are people that go out of there *(mm)* because I saw two or three *(yeah)*, but if you're going to be honest *(mm-hm)*, when you're in there it's… and that's where they deserve all the admiration they get, these people, because they see it day in, day out *(mm)*. And there's plenty of them, loads and loads of staff, they'd do anything for you." (Len, male, husband and carer, bereavement interview)

6.2.3.1.3 The ticking clock

Chris and Faye told a distinct prognosis story but for others it was a subtle thread throughout the narrative. These participants knew there was no cure but were uncertain of how long they had left. Time was ticking for all the participants in this study, with the exception of Gordon as described in section 6.2.3.1.1. For Chris and Faye the alarm clock had been set when they were told were dying but others were waiting for someone

(namely the oncologist) to set the alarm. Several questions arose in light of the way people spoke about this. Firstly, what happened when the alarm was set? Ian had been given a two year prognosis at the time of his diagnosis so as far as he was concerned, his alarm clock had been set then and, as he was approaching the two year prognosis he had been given, he was waiting for the alarm to go off at which time he would die. Ian felt in limbo and he expressed the need for an update about his condition. Ian was conflicted at T3 as the quotes to follow illustrates. Ian felt frustrated and upset with the lack of communication he had experienced and the uncertainty about when the alarm was going to sound, as the quotes below illustrates.

> "But it's just, I feel I've got more than two years to go, you know, but I don't know, you know" (Ian, 65 year old male, patient, time 3)

> "But what a job I'm having getting to know how I'm getting on. It's my life, eh? I should be told "listen, you've got this" or "you're doing that" or "we're giving you this" or "your tumours are growing" (Ian, 65 year old male, patient, time 3)

Compared with Ian's two year prognosis, Chris and Faye had been given short prognoses which meant systems were put in place with the GP and palliative care services. Unlike Ian, they did not question how long they had left or doubted whether in fact, the prognosis was inaccurate, rather they dealt with the now and did not speak much of the future other than Faye did not want to be in pain, and Chris and Hazel wanted to be together. In fact, in contrast to Ian's chaotic narrative, those of Chris and Faye seemed organised and structured.

In comparison to Chris, Faye, and Ian, Andrew had not been given a prognosis in terms of months or years. He and Gill were fully aware that although there was no cure for his condition and although the clock was ticking, the alarm had not been set. The quote to follow illustrates this,

> Gill "…the longer the better, obviously, this is with him *(mm)* so there is no betterment – there's a better… a quality, but there will be no cure" *(yeah)* and she went "oh, awful" and then I says to her "but he's not dying" *(yeah)* because she's like "oh, well I…", I says "no, no, it's not at that stage *(yeah)*, that's a long… hopefully a long way off" *(yeah)*. Because immediately when I said to her "there isn't a cure" she was like "well, how…" – because she works in a hospice – "how long's he

got?" you know! *(mm)* And I said "there is no time but there is no cure." (Gill, female, sister and carer, time 3)

Andrew had devised his own strategy for dealing with the uncertainty of his future and when his alarm might be set. Instead of focusing on the unknown and seeking answers about his future and how long he might have left to live. Andrew set goals of events he wished to attend. The targets varied in length from days to years, thereby confirming the uncertainty of his future. In the first quote, note that on a day to day basis he focuses on going to work, weekly he watches his son play football.

> "just sort of waken up and say "right, I'm going to work today, let's get on with it" *(yeah)*, "I'm going here today, let's get on with it", "I'm going to watch my son playing football *(yeah)*, let's get on…" *(yeah)* and just basically take it as a day, as it comes" (Andrew, 57 year old male, patient, time 3)

In the second quote his targets are slightly further away; in fact seeing his grandson go to school was several years away.

> "let's be honest about it, you want to live as long as you can *(of course)* so in that respect it doesn't really bother me, THAT situation *(yeah)*, because I know there's nothing can be done, er… And so I try to set myself goals, like I say to myself "the wee fella's one so I'd like to be *(mm-hm)* around when he goes to school" *(yeah, yeah)* and I think that way *(yeah)*. And then my granddaughter who's five has got a show, she's got a gymnastics show at [sport's centre] *(mm-hm)* and these things in December *(yeah)*, I want to, ken… And so I just try and, in my own mind, set myself goals *(yeah)* as much as… And I want to try and be *(yeah)* around as long as I can" (Andrew, 57 year old male, patient, time 3)

Secondly, how do the social and cultural contexts change in light of this ticking clock? Participants spoke about their ability to participate in social activities; maintain old, and develop new relationships. For example, Chris spoke of his increasing isolation from his friends as he could no longer go to the rugby or out for walks with them. Although they still visited him occasionally he now felt like passive participant in the relationship. Likewise, Ann felt unable to maintain old relationships as her condition was unchanged from T2 meaning it was difficult to go out for long periods of time and her condition prevented her from eating and drinking; a common social norm. However, unlike Ann and Chris, Ian ensured he was still active and visible within the community which helped him maintain his sense of identity. Moreover, Ian's ability to continue living in

spite of the uncertainty which surrounded his diagnosis enabled him to continue to form new relationships. Ian was unique in terms of his very active social life but he recognised the importance of companionship in life. Ian was neither married, nor co-habiting and the challenging relationship he had with his children meant he craved a shared experience.

6.2.3.1.4 Hope

For most of the participants hope was aligned with treatment, as it was seen as the only lifeline. Andrew was hopeful that a new treatment might be introduced that could potentially prolong his life given that he was having limited success with the present chemotherapy regimens, leaving him few options for the future.

> "they also said at the time "there might be something that comes along, you never know" *(yeah)* so therefore that's in the back of your mind as well *(yeah)"* (Andrew, 57 year old male, time 3)

Similarly Brian was experiencing complications with his chemotherapy regimen at the time of the interview and was hopeful that the physicians would find an alternative so he could continue treatment. Brian's fear that an alternative might not be available, or that it might not be as successful was obvious,

> "Well, obviously I've got a little hope that things will work out OK" (Brian, 59 year old male, patient, time 3)

> "obviously, you want the treatment to work and I did try and I tried and I tried *(mm-hm)* with the tablets but it was a losing battle, you know?" (Brian, 59 year old male, patient, time 3)

Brian wanted to assure me that he had tried his best to take the tablets but had found it impossible hence his use of the word obviously, which was also a sign to me that he had not given up hope. Likewise, he was worried that he had failed the professionals who were looking after him.

At the time of interview three Ian had not received chemotherapy for approximately nine months which left him feeling neglected by the health professionals. Consequently, in order to feel like he was in control and was doing something to help himself Ian adhered to a strict diet and had explored the role of alternative therapies.

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"another thing that's really hard, 17/10/09 *(mm-hm)*, that's when my chemotherapy stopped *(yeah)*. I've never had a tablet or anything from [name of hospital]. How's that? There's something wrong there" (Ian, 65 year old male, patient, time 3)

6.2.3.2 Altered personal relationships

Participants reflected upon their personal relationships and how they had altered in the context of their illness. Participants worried about becoming a burden on their loved ones and for this reason it was their relationships with their spouses that were discussed. As I described above, both Faye and Chris feared that they would become a burden on their families, although they did not feel like they were at the time of the third interview. In contrast, Ann reflected on the strain that her husband, and main carer was under. Due to Ann's recent fall, and the subsequent problems with her mobility, his role as caregiver had increased.

"And it's a terrible strain on [name of husband] and he's not coping too well (oh, that's… it really is…). Well, it's hard doing these things, you know. But by night time he's had enough, you know." (Ann, 67 year old female, patient, time 3)

Ann felt she was a burden on her husband and she expressed her relief that he was still able to go swimming, a hobby they had both enjoyed before the cancer. When asked if her husband still went swimming she replied,

"Most days, yeah, thank god." (Ann, 67 year old female, patient, time 3)

The findings suggest that Ann and her husband were gradually becoming more isolated, particularly as she could no longer eat or drink so preferred not to go out. In fact in the days prior to the interview, Ann's husband had contacted the social work department to ask for help. Ann's husband was of a similar age to her so the physical burden associated with helping Ann in and out of bed, and up and down the stairs. In the quote below Ann describes how she waited for her husband to go swimming before she made herself more comfortable. Ann was trying to remove some of the strain on her husband.

"I need to adjust the armchair – nothing wrong with the armchair, the thing is it goes down at the back and hollow, it's not straight enough *(right)* so I'm going to get some different cushions and try a different arrangement. I'll wait till he's gone to the pool and I'll do it!" (Ann, 67 year old female, patient, time 3)

Gordon described the benefits of having shared the experience with his wife Kate in the quote below. This echoed the feelings of others in the group who had a companion with whom they confided.

> "she was there all the time to help me *(yeah)*. And I think if anyone goes through something like that without support of a partner or a wife, it must be an awful lot more difficult *(yeah)*. Because you've always got someone you can talk to." (Gordon, 65 year old male, patient, time 3)

6.2.3.3 Relationships with health professionals

Participants talked about needing and receiving support from a variety of professional agencies including; GPs, district nurses, hospice nurses and social workers. This is in contrast to the earlier interviews, when health care professionals, particularly those from the hospital, dominated the relational experience. Chris and Faye both felt happy that the necessary agencies were in place when they were required, but the same could not be said for Ann and her husband, as I described above. This suggests that until a terminal prognosis is given (perhaps weeks or months) there is not the same drive to get such systems in place. It seems that the onus was on Ann and her husband to seek help and contact the relevant people.

Another source of support that was cited by Brian was the local Maggie's Centre. Brian, a quiet man, had expressed that he found it difficult to talk to people so I was surprised when he told me that he visited the Centre. Interestingly, he went on to tell me why he went when he did, and it was because he was feeling stronger, rather than depressed as he had been previously. Brian had to feel strong enough to confront his issues. It was encouraging that Brian felt he found somewhere he could go for support even though he did not feel it necessary to talk at the time. He had acknowledged the importance of having an outlet should he need it.

> "Each time I thought about it but I went "well, maybe the next time" *(laughs)*. I went in this time! I do find it sometimes quite difficult kind of talking to people *(mm-hm)* that… ken, if I don't know them *(mm-hm)* or *(yeah)* introducing yourself and "tell me what…" *(yeah)* whatever's up. But I'm glad I went in, ken, they made me very welcome, I must admit, and gave me information away with me *(great!)*. And they just says "even though you're not wanting to talk to us, if you just want to come in for a cup of coffee and that" *(yeah)* they said "we have a quiet area as well *(yeah)* where

you can sit" and she said "if you want to read your paper and cup of coffee, just come in" she said "we're here, come at any time." (Brian, 59 year old male, patient, time 3)

Interestingly, participants spoke less and less about health professionals as the study progressed.

6.2.3.4 Summary – The final interview

The prognosis story – the last chapter of the overall narrative, replaced the cancer story from T2, for those who were in the final stages. The prognosis narratives were generally situated at the beginning of the interview and thus indicated the tone and main topics to be discussed throughout. For those who were relatively stable, the cancer story from T2 continued. Overall, thoughts about their prognosis, and the uncertainty of what lay ahead for participants was interwoven through the themes presented above. Participants experienced changes in parallel with the greater feeling of certainty that death was approaching. For example, when death was imminent, home became a more meaningful place and participants' relationships changed in light of their increasing frailness and dependency upon others.

The notion that a clock was ticking seemed present where it had not been before. Participants reacted to this in various ways; for example Andrew set himself targets of events he wished to achieve whereas Faye and Chris in light of their terminal prognosis and the alarm clock being set wanted to spend time with their families.

6.3 Part II – Discussion

6.3.1 Overview of the findings

6.3.1.1 The beginning, the middle and the end

In this study I sought to preserve the participants' narratives as they wanted them to be heard. To do this I opened each interview by asking what had been happening to them. Throughout the interviews I allowed silences to be processed in as natural a way as possible, and thus I refrained from interrupting the participants. The result of this was that the stories of some participants were pages and pages long. Moreover, the VCRM narrative analysis privileged the stories in the context in which they were told.

At the first interview, all the participants told their diagnosis story. Although they told the stories in different ways, there was a well defined and detailed narrative which included first signs and symptoms, diagnosis, surgery and treatment. This is consistent with the findings of Worster and Holmes (2008) who report that the participants in their study had an overwhelming need to tell the diagnosis story. Indeed, Worster and Holmes (2008) had difficulty in exploring their original aim which was to describe the pre-operative period when participants were awaiting surgery to remove the colorectal tumour (Worster et al., 2008). Like Worster and Holmes (2008), Taylor (2010) found that the diagnosis story was prevalent throughout her 16 interviews with CRC patients (Taylor et al., 2010). Likewise, those who were near the end of their lives narrated a clear end to their story. However, although there was a clear diagnosis story and a clear end for those who were dying, the middle of the overall cancer story was less well defined. What I have entitled the cancer story at T2, which replaced the diagnosis story, took a more nebulous form. This was particularly the case if the participants reported that there had been little change, when compared to those instances where participants described a critical event, like a fall, a hospital admission or deterioration in their condition.

The narratives in this study; beginning, middle and end shared a common purpose, in that they were used to introduce the plot/sub-plots and the characters/relationships. It is interesting to note which characters came in, and went out of the story over time. For example, the participants spoke about the role of the health professionals during the diagnosis story, but as the study progressed there was less and less talk of them and interestingly at T3 the focus was familial relationships. One reason for this could be that throughout the diagnosis story the health professionals were central characters, but as the story progressed and participants were negotiating their increasing social isolation family and friends took on a more important role. Paradoxically, the health professionals were talked about least for those who were very close to death when it might have thought that they had a greater role to play. This finds support in Bingley et al's (2006) account of their bibliometric analysis of the narratives of people facing death since the 1950s. The authors found that when those who were dying spoke about death, it was a profoundly personal account of the experience and one which rarely involved the role and relationship with professionals (Bingley et al., 2006). The importance of 'home' which arose as a theme at T3 is further evidence to support the deeply personal experience which characterises the end of life. Broom and Cavenagh (2011) found that the participants in their qualitative study, about the meanings and experiences of being in the hospice, applied particular meanings to home in that it helped participants maintain a sense of self (Broom & Cavenagh, 2011).

Death was present as a character in the beginning, the middle and in the end. Participants described being confronted with their mortality in the diagnosis story which is the most likely explanation for the two main narrative threads, which explain the themes above and are discussed in the section to follow.

6.3.1.2 The narrative threads

I used Saldana's (2003) notion of the through-line to rise above the data and to achieve richer interpretation[22] (Saldana, 2003). Saldana (2003) suggested that QL studies benefit from having a through-line which connects and summarises the observations of the researcher. In some cases the through-line may reveal itself in a 'eureka' moment but in others, such is the case here, it occurs through the interpretation of the longitudinal data. Unlike Saldana (2003) I am not suggesting that there is one through-line that links all the themes together, rather that there are two broad threads that describe the data and how it changed over time.

6.3.1.2.1 Constrained in space

Over time the participants' narratives highlighted changes in their relationships which for many resulted in social isolation and feelings of being constrained in space. At T1, many participants were trying to maintain a sense of normality in their professional and social lives but there were challenges due to the physical restrictions that the illness caused. Moreover the participants were challenged by their changing perception of themselves and how others viewed them. This was particularly the case when their appearance changed as the illness progressed which consequently emphasised their desire not to be viewed as victims of cancer. These findings are consistent with those of Taylor (2001) and Little et al (1998) who both reported that social isolation resulted after a diagnosis of CRC (Taylor, 2001; Little et al., 1998). For example Little et al (1998) found that for participants who were later in the illness experience there was a distancing from social familiars. Both of these studies referred to the embarrassment caused by the CRC, however in this study the physical changes that led to changes in participants' perception of themselves were fairly generic of the cancer experience (for example weight loss/gain, hair loss, and general frailty). There was one exception to this and that was in the case of Ann who had a permanent stoma and suffered problems

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[22] A table of Saldana's questions to guide the analysis of QL data can be found in chapter four.

following extensive abdominal surgery. This suggests that there may be some experiences that are specific to those with a permanent stoma, which is demonstrated by the body of stoma literature which already exists.

6.3.1.2.2 Constrained in time

The second of these broad themes is how the participants talked about, and were constrained in time. The participants described time in two ways; firstly there was chronological time, which was linear in nature and represented the events, tests, scans and treatment at the beginning, the middle and the end of the illness experience and is self-evident throughout the themes above. I would concur with Little et al (1998) who found that participants described a sense of urgency when they were first diagnosed. As was described in section 6.2.1.5 (page 130) this was sometimes inferred by how the participants used certain words or phrases (Little et al., 1998).

Secondly there was biographical time, which incorporates how the participants contemplated the past, the present and the future and is non-linear. For example at T1 the participants described having been confronted by their own mortality at the time of the diagnosis and later if they received surgery. They were also constrained by the prognosis, so the time they had left became important and meaningful. Thompson (2007) also found that temporal notions profoundly affected the lives of women with ovarian cancer (Thompson, 2007). At T1, participants also described having sought meaning in their past. They tried to make sense of, and embed the cancer in their lives to secure a sense of coherence (Ramfelt et al., 2002). Shaha and Cox (2003) reported how patients with CRC questioned the meaning of their lives (Shaha et al., 2003). Moreover Lee and colleagues (2006) found that those who reflected on the experience of cancer in relation to their biographies and on their own mortality were more successful in a meaning-making intervention than those who were in their control group and receiving normal care (Lee et al., 2006).

At T2 participants moved from reflections on the past to the future and about the legacy they wanted to leave behind them. Thus they were thinking about the future, after they had passed away. In this way they were negotiating an after-death identity, as described by Exley (1999) – a theme that I elaborate upon in chapter seven. At T3 the interviews portrayed a sense of increasing uncertainty for those who had not been given a terminal prognosis – in other words, when the alarm had not been set.

In response to being constrained by time, accounts of uncertainty dominated the transcripts, particularly at T1 and T2. There was uncertainty about how the illness would progress, would it be slow or fast? Would it be painful or peaceful? Lawton (2000) describes that the slow process of dying with increasing social isolation caused more distress to the hospice patients in her study than the actual death itself (Lawton, 2000). In this study there was also uncertainty about how long participants felt, or had been told they had to live. Uncertainty is widely cited as a response to experiencing cancer. Within the CRC literature, it was often described in response to illness progression and disease recurrence, and as Browne and colleagues (2011) report, it was identified at all stages of the illness trajectory (Browne et al., 2011). For those with advanced disease Sjovall et al (2011) reported that uncertainty was most commonly described about the future and how their families would cope which is consistent with the findings reported earlier in this chapter (Sjovall et al., 2011). This study supports Browne et al's (2011) findings that uncertainty was seen throughout the illness trajectory, but for the participants in this study, over time, the analysis revealed the struggle of living with the uncertainty of what lay ahead within the certainty of death.

Frank (1995) described that in order to tell a story, the narrator needs a sense of temporality (Frank, 1995). In this study the participants were constrained by time and there was a dual narrative of living with the uncertainty of how the illness would progress and the certainty of death. The dual narrative of uncertainty and certainty could

explain why the cancer story at T2 was unclear and undefined compared with the diagnosis and prognosis stories.

6.3.1.3 Liminality – a framework for understanding the experience of metastatic CRC?

Together, the broad themes of being constrained in time and space correspond to Little et al's (1998) description of boundedness, where the world contracts after the diagnosis and the ill person feels bounded in time and space. Little and colleagues (1998) described three themes, one of which is boundedness, in their narrative study of the experiences of CRC. Their study also found that participants suffered from 'communicative alienation', where there is distancing from the patient's social reality when they have cancer as was described in the theme of social isolation. The third theme of 'cancer patientness' is characterised by how the patient identifies themselves as cancer patients. Although evident throughout the transcripts in this study, particularly when the participants' physical appearance changed, it was not present to the same extent as Little et al (1998) described. This could be due to the high proportion of participants with a permanent stoma in Little et al's (1998) study. Little et al (1998) proposed that together, these three themes suggest that the patient with CRC enters a liminal phase after they have been diagnosed (Little et al., 1998).

The concept of liminality originated from the work of Arnold Van Gennep, an anthropologist, at the beginning of the 1900's. It originates from his work into the social rites of passage and in essence describes the transition between different phases in life, for example, pregnancy and childbirth, marriage and death (Van Gennep, 1960). According to Van Gennep (1960) there are three phases involved in the transition; pre-liminal; liminal and post-liminal. Hockey (2002) summarised these as 1) moving out of a phase or social status (pre-liminal phase), 2) an ambiguous time of betwixt and between (liminal phase) and 3) entry into a new social position (post-liminal) (Hockey, 2002; Van Gennep, 1960). Those in the liminal phase are considered vulnerable and

contaminated, thus dangerous to others (Douglas, 1985; Lawton, 2000; Froggatt, 1997; Murphy et al., 1988).

However, recently the notion of liminality has been proffered as a framework for understanding the experience of those with; cancer (Blows et al., 2012; Little et al., 1998; Navon & Morag, 2004; Cayless et al., 2010; Thompson, 2007); disability (Murphy et al., 1988); mental health (Shomaker, 1989) and chronic illness (Tierney et al., 2012). Liminality in the context of the embodied experience of illness is described as a state of transition, where the ill person's status is undefined, ambiguous and often paradoxical (Little et al., 1998; Blows et al., 2012; Cayless et al., 2010). For example, in terms of disability Murphy et al (1988) described that the person with disability is seen as neither ill, nor healthy (Murphy et al., 1988). Shomaker (1989) described those in with Alzheimer's disease as simultaneously dead and alive (Shomaker, 1989). However, in comparison to Van Gennep's (1960) stages of liminality, Little et al (1998), the first to describe liminality as a category of the cancer experience, argued that the liminal experience of cancer is a process (Little et al., 1998).

Since the work of Little and colleagues (1998) a number of authors have considered the concept of liminality to describe the experience of cancer. However, as was evident from the literature review, this is generally in relation to surviving cancer, not dying from it. Thompson (2007) proposed that the experience of women with ovarian cancer is a liminal one, yet she argues it is different to that described by Little et al (1998). Thompson (2007), like Little et al (1998) found that the women felt restricted in time but they did not feel restricted in space. Interestingly, Thompson (2007) described that the women experienced feelings of empowerment and they used the liminal experience to deepen their relationships with the self and others. She suggested that the liminal experience for those with ovarian cancer is unique, in that they experience proximity to death yet feel well (Thompson, 2007). One noticeable limitation of Thomson's (2007)

study is that the women were recruited from a support group meaning their experiences may have differed from those who had not experienced support (Blows et al., 2012).

Blows et al (2012) synthesised studies which explored liminality. The authors found ten studies to include in their review which included Little et al's (1998) study, two studies about men with prostate cancer, Thompson's (2007) study, and several that focused on the cancer experience more generally. Blows et al (2012) concluded that liminality is a useful framework for understanding the experience of cancer survivorship, but can the same be said for understanding the experience of the terminal phase of cancer? (Blows et al., 2012).

The data presented in this chapter supports Little et al's (1998) assertion that the experience of CRC can be categorised as a liminal one. Little et al (1998) found that the CRC patients enter a stage of liminality between illness and health when they are first diagnosed, and that the initial phase is characterised by uncertainty, disorientation and loss of control (Little et al., 1998). I too found that the participants in this study experienced uncertainty, boundedness in time and space and feelings of loss of control which point to the liminal experience. The diagnosis stories that were told in this PhD study suggest that liminality was the result of the contradiction of living between health and illness which supports Little et al (1998) (Little et al., 1998). Despite confronting their own mortality, a number of the participants in this PhD study commented on how well they felt. This finds support in Thompson's (2007) study which found that the women with ovarian cancer described a dual narrative of feeling close to death yet feeling well (Thompson, 2007).

According to Little et al (1998), their participants moved towards a suspended liminality, where they re-constructed meaning for their experiences through narrative and where they probably remained as cancer patients for the rest of their lives (Little et al., 1998). Thompson (2007) agreed with Little et al (1998) that the liminal state is a

permanent one (Thompson, 2007). This concurs with Frank's (1995) description of the remission society but is in contrast to Van Gennep's (1960) assertion that there is a post-liminal phase where the individual is re-incorporated into a new social group (Frank, 1995; Van Gennep, 1960).

In contrast, in the period before their death some of the participants in this PhD study seemed to return to their 'master' identity and thus moved away from one which was characterised by being a cancer patient. The theme about the meaning of home is evidence of this and it is an issue which I will elaborate upon in the chapter to follow, when I explore the individual narratives over time in more depth. This may suggest that those who are dying enter a post-liminal phase which bears resemblance to their pre-liminal phase. However, Lawton (2000) suggested that at an individualistic level the process of dying is liminal, rather than the death itself, which suggests a continuum of liminality not the re-entry into a pre-liminal identity (Lawton, 2000). In contrast to this PhD study, Lawton's (2000) ethnography was conducted in a hospice, a place which is itself described as liminal, where those who are ill are neither in the space of the living, nor in the space of the dead (Broom et al., 2011; Lawton, 2000). Further work could compare the liminal period for those dying in the hospice compared to those dying at home.

Although at the beginning of this study, the concept of liminality was understood as being betwixt and between health and illness, latterly it was understood to be between illness and death and, moreover the paradox of living with the uncertainty of how the illness would progress with the certainty of death. This contradictory situation that the participants found themselves in, could explain why the middle of the narrative, the cancer story seems ill-defined when compared with the beginning in the end. Living with such uncertainty compromised the participants' narrative resources.

6.4 Concluding remarks

This chapter addressed how the experiences of the group as a whole changed across time. Although participants were at different stages of the illness trajectory, at different time points, there was always a beginning – a well-rehearsed diagnosis story; a middle – albeit undefined; and for some, an end – the prognosis story. Moreover there were two broad threads which were found to be woven through the data which resemble what Saldana (2003) described the through-line (Saldana, 2003).

The first was that participants felt constrained in space after diagnosis. Their increasing frailty and changing appearance meant that they were gradually distanced from social realities and as a result they feel isolated and experience a change in their personal relationships. The second was that participants felt constrained by time. They were confronted with their own mortality and their perception of time changed, meaning accounts of uncertainty dominated the transcripts. Participants used biographical time to make sense of their experiences in the past and to define their futures while they were still able to do so.

The broad narrative threads of being constrained in space and time suggest that the experience of metastatic CRC is a liminal one. Participants were in a liminal phase between illness and health at the beginning when they felt and looked relatively well, and illness and death at the end. This study did not set out to explore the process of liminality but it has shown to be a useful concept for understanding the experience of terminal cancer. The findings in this chapter suggest that being liminal may compromise the ill person's narrative resources and their ability to make sense of their illness and even their lives (Mathieson et al., 1995). As was mentioned earlier, Douglas (1985) described those who are liminal as vulnerable, and polluters to those around them due to their ambiguous status (page 169) (Douglas, 1985). If this is indeed the case it could lead to even greater social isolation. Further research could explore the liminal experience of dying at home and in the hospice particularly in relation to identity. Does

a sense of self which resembles the pre-illness identity allow people to re-incorporate into society before they die?

It was out with the scope of this study to follow all the participants until their deaths, which may have given me a better understanding of this period. Nevertheless the QL design allowed me to follow the participants through the liminal period which has provided insight into the challenges of living in an ambiguous state which is characterised by uncertainty.

CHAPTER SEVEN
The process of change: Six case histories

7.1 Introduction

In chapter six I explored how the accounts of the participants' experiences changed across time and discussed the broad threads that were woven through the data. In this chapter I consider more closely the process of change - process being the second key feature of QLR. Like chapter six, this chapter is divided into two parts. In part I of this chapter six case histories are presented alongside diagrammatic timelines. Part II provides an overview of common processes within the group and will draw on key theories to explain the findings.

7.2 Part I – Six case histories

Although the time point analysis which was presented in chapter six was useful for understanding the experiences of the group of participants, the case histories presented below provide an in-depth look at the individual process of change. To follow are the findings from six narrative case histories. Each of these was subjected to a longitudinal narrative analysis using the VCRM which I detailed in chapter four (page 93). These six participants were selected to represent the diversity of the group as a whole in terms of gender, number of interviews and the presence of an informal carer and a range of experiences. I will present a synopsis of each participant's case history[23] and provide a diagrammatic timeline - where the X axis represents time and the Y axis represents the events that took place in the narratives and the themes that were generated through the analysis. The green boxes **represent the key events in the overall plot** of the narrative. The boxes below the X axis represent the main themes/threads from the narratives

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[23] A synopsis of each participant's story has been provided as the full analyses were too long to include in this thesis.

(**orange = related to self**; **red = death**; **blue = relationships**; **aqua = aspects of the carer story**). In the pink boxes I have also included some of **my reflections from the interviews** to contextualise the stories.

7.2.1 Ann's story
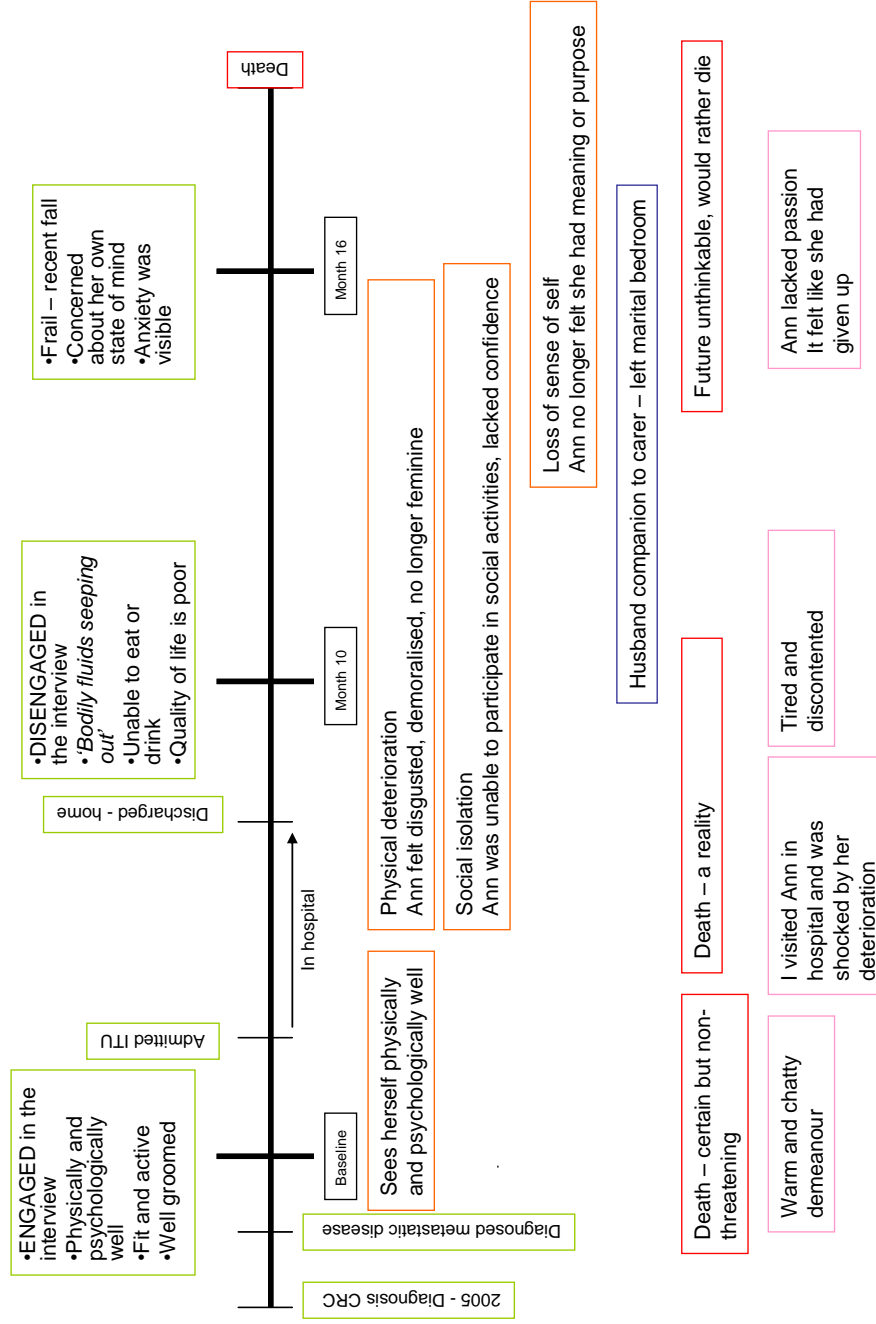
Figure 7. Timeline representing Ann's account of her experience of metastatic colorectal cancer over time

Timeline markers: 2005 - Diagnosis CRC — Diagnosed metastatic disease — Baseline — Admitted ITU — In hospital — Discharged - home — Month 10 — Month 16 — Death

- ENGAGED in the interview
- Physically and psychologically well
- Fit and active
- Well groomed

Sees herself physically and psychologically well

- DISENGAGED in the interview
- 'Bodily fluids seeping out'
- Unable to eat or drink
- Quality of life is poor

- Frail – recent fall
- Concerned about her own state of mind
- Anxiety was visible

Physical deterioration
Ann felt disgusted, demoralised, no longer feminine

Social isolation
Ann was unable to participate in social activities, lacked confidence

Loss of sense of self
Ann no longer felt she had meaning or purpose

Husband companion to carer – left marital bedroom

Future unthinkable, would rather die

Death – certain but non-threatening

Death – a reality

Ann lacked passion
It felt like she had given up

Warm and chatty demeanour

I visited Ann in hospital and was shocked by her deterioration

Tired and discontented

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Ann was 67 years old when we first met and had been retired for several years. She lived with her husband and had a daughter and two step-daughters who lived reasonably nearby and visited often. Although Ann was happy to participate in the study herself she was reluctant for me to talk to her husband and as a result he was not recruited as her informal carer. As the timeline in figure seven (page 177) shows, Ann and I met at recruitment, month ten and month 16 of the study, which was because she spent five months in hospital between T1 and T2.

Ann was first diagnosed with colorectal cancer in 2005 and, although she had surgery to remove the tumour, a routine colonoscopy in 2006 revealed another tumour in the bowel. Ann required a second operation to her bowel and due to the size of the tumour she needed a permanent stoma[24]. Ann was diagnosed with metastases in her peritoneum in 2007, not long after the second surgery. At the time of the first interview Ann appeared to be well and in good spirits. She was swimming and gardening most days and enjoyed socialising with her friends and family. In fact Ann described how she sometimes wondered whether the doctors were right about her illness as she felt so well.

> "I mean I feel physically as well as I've ever felt in my life. Even now, you know, knowing what I know. I just find it you know. Feel like saying to oncologist I mean are you sure (laughs)" (Ann, 67 year old female, patient, time 1)

Ann's first interview was in November 2008 and in January 2009, following a routine CT scan, Ann was given another course of IV chemotherapy after which she suffered a violent reaction requiring extensive abdominal surgery. As the timeline shows, Ann spent several months in hospital, but having survived the 'touch and go' surgery she was unable to eat or drink. At the second interview Ann was being fed intravenously and because her abdomen was leaking bodily fluids on a regular basis she had moved out of her marital bedroom and into the small single bedroom where medical equipment and spare linen towered high beside her. The pink boxes on the timeline illustrate the change between interview one, where I found Ann to be chatty and optimistic, and

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[24] Ann was the only participant in the study to have a permanent stoma.

interview two where she was tired and discontented., Ann was 'matter of fact' about what had happened to her and in comparison to our first interview seemed disengaged. Although Ann's physical condition had marginally improved at the time of interview three, she confessed that she was concerned about her own state of mind and her anxiety was visible to me.

The thread throughout Ann's narrative is about her progressive loss of sense of self. At interview two Ann described the result of the physical restrictions that she experienced, as I have illustrated what the orange box in the timeline above. Ann's previously fit and generally healthy body now had 'bodily fluids seeping out' which left her feeling demoralised and unfeminine.

> "I don't have much of a quality of life right now, can't go anywhere you know I mean I'm sitting here on a waterproof thing incase I leak I mean there were times where I would stand up and it would start running down my leg because the bag had opened up" (Ann, 67 year old female, patient, time 2)

The physical restrictions that Ann experienced and the loss of self esteem that was evident as a result, led to social isolation, which I have also illustrated in the orange box on the timeline. Ann felt unable to socialise due to her frail and dispirited state and on a more rudimentary level she could not participate in the social norms of eating and drinking. This quote emphasises the change in Ann's situation but also illustrates the distance she felt from her pre-illness social world.

> "you know swimming every day and out for wee runs in the car and a wee picnic somewhere you know (yeah). I mean I can't even do that, I can't even have a cup of coffee you know what I mean. You know people say pop round for a coffee and well I can't you know" (Ann, 67 year old female, patient, time 2)

As the timeline illustrates, at interview three Ann no longer spoke of the things that mattered to her and she no longer saw the meaning in her life. Ann's sense of self was threatened by the physical restrictions she had to endure and her increasing social isolation. She did not recognise the way she was coping with her illness at interview three, nor did she feel like an autonomous individual. In the quote to follow Ann confessed to being confused about her negative response to her situation – By the time

of the third interview Ann did not know who she was anymore and was frustrated that she could not get back to her old self.

> "I mean I'm not a negative person. And I don't understand why I've ended up like this because it's not me, you know? *(mm-hm)* Well, it obviously IS me, but a different part of me and a different side of me which has only just surfaced, you know, because of circumstances" (Ann, 67 year old female, patient, time 3)

Ann's husband transitioned from companion to carer in parallel with her deteriorating condition. After my third interview with Ann, she asked me if I would have a chat with her husband. Admittedly I was rather surprised at the request as Ann did not want him to be involved in the study but was flattered when Ann said "he doesn't like many people but he does like you." As Ann's husband was not consented to participate in the study I did not record the interaction but it was evident that they were struggling to cope and he was missing who his wife had once been.

When I said my final goodbye to Ann her passion and vigour for life had been quashed, so I was not surprised to hear she had passed away not long after the last interview.

7.2.2 Duncan's story

Hospital as a child

Mother's death

Marriage ended

Diagnosed with Cancer

Baseline

Month 6

Death

Diagnosis total shock
Prognosis 3 months –
4 years
Nothing else can be
worse than dying so
he felt indestructible
Working so kept busy
and tired out

Cancer spread to
lungs
Further
chemotherapy

Why me? He stayed fit, a non-smoker

Portrays the SINNER
Confessing his sins to be with his mother in heaven

It doesn't matter who you are

Portrays the SAINT as he wants to leave
a positive legacy

Good storyteller
Candid
I felt like he was confessing his sins

Female protagonists dominate the narrative
These heroines are missing from the lived experience leaving Duncan yearning for companionship

Figure 8. Timeline representing Duncan's account of his experience of metastatic colorectal cancer over time

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Duncan, aged 57 years, was diagnosed with rectal cancer and accompanying liver metastases ten months prior to his recruitment into the study. He lived with his octogenarian father, having separated from his wife several years earlier. Duncan had two sons who he saw regularly and lived nearby. As the timeline in figure eight (page 181) highlights, Duncan and I met on only two occasions as sadly, after several failed attempts to contact him for our third interview, I found out he had passed away.

Duncan's initial diagnosis had come as a shock to him as he felt perfectly well prior to an episode of bleeding from his rectum which forced him to visit the GP. Until T1 his illness had progressed slowly and although he experienced side effects from the chemotherapy he remained reasonably well. However, when we met six months later at T2, a CT scan showed evidence that the cancer had spread to his lungs, in addition to the existing liver metastases so he had to endure another course of chemotherapy. In spite of Duncan's deteriorating illness he remained looking fit and well.

As I have illustrated on the timeline, at the first interview Duncan told me that his initial reaction to having cancer was to ask 'why me?' As far as he was concerned he had led a healthy life; he did not smoke, he drank socially, he kept fit and although he admitted to eating too much fast food he considered himself to be healthy. By T2, having spent a considerable amount of time in the chemotherapy ward Duncan reasoned that cancer affected all types of people, and although he still wondered why it happened to him he preferred to keep active and positive rather than focus on the negative. The quote below illustrates this transition and highlights Duncan's realisation about the fragility of life in general.

> "I lead a fairly healthy life, type of thing, you say why me? You know? But if it's for you, it's for you, eh, it's just (*mm)* especially when you go across to the chemo ward and you see all age groups there, all shapes, sizes, it doesn't matter who you are" (Duncan, 57 year old male, patient, time 2)

Three sub-plots were evident in Duncan's overall story and although they occurred prior to the cancer, as the timeline illustrates, they shaped Duncan's overall experience. The

first a complicated nine month stay in hospital with tuberculosis when he was a child. The second was the death of his mother, and the third was the break down of his marriage. These sub-narratives abridged both interviews, but Duncan's understanding of how they shaped his experience of cancer evolved. For the most part Duncan used interview one to recount the past; he told the sub-story and how it affected him at the time, whereas at interview two he spoke about how each of these sub-narrative plots informed his present and ultimately how it might inform his coping strategies for the future. In each of these stories there was a female protagonist; in the first, a nurse (and his mother); in the second, his mother and in the third his wife. Although protagonists in his story, Duncan felt he had been abandoned by these women in each of the sub-narratives.

I have represented the change in the way Duncan spoke about himself in the orange boxes on the timeline. At the first interview, Duncan spoke about himself in a derogatory way through the stories he told about his destructive behaviour following the break down of his marriage. In fact my field notes reminded me, as I have illustrated in the pink box that after the first interview I felt as I imagine a priest may feel after a confession might feel; as though Duncan was seeking atonement for what he perceived as the sins he had committed. Duncan seemed concerned that he would not get into heaven to be with his mother as the quote below, from T1 illustrates.

> "I want tae get in there like eh. I might just get as a day visitor or I might just get a half day Wednesday's when maybe have a half day for visitors I might get up there in the half days. But if I tell myself I'm gonnae go to purgatory I'll never ever get up there" (Duncan, 57 year old male, patient, time 1)

As far as Duncan was concerned, the break up of his marriage was the catalyst for a number of damaging incidents involving violence and deception which followed. Five years following the split from his wife Duncan was diagnosed with cancer, and by this time, Duncan felt his life was worthless, so much so that he had wished the cancer upon himself as the quote to follow illustrates.

"When (wife) first broke up, when we broke up I was desolate, I was just, I just float about the house and that and keep myself busy. I wanted cancer. Now I've got it" (Duncan, 57 year old male, patient, time 1)

Duncan described how the realisation that he was going to die of the cancer (Duncan had been given a prognosis of between three months and four years) made him feel indestructible in the sense that nothing could rival this worst case scenario.

"I got the cancer I felt I was indestructible in a sense but nothing can happen. What can anybody do to me? They cannae do any more to me. They can't do any worse than what I've got (uhuh) cos I'm dying." (Duncan, 57 year old male, patient, time 1)

The tone of interview two was different when compared with interview one. Instead of focusing on the sins he felt he had committed Duncan told me about some of the good deeds he had done since the last interview. For example he told a story about helping a customer at his work; he gave another customer flowers on her birthday; he spoke about lending his family money when they needed it. As the orange boxes on the timeline suggest Duncan no longer wanted to be seen as the sinner he portrayed at interview one, instead he wanted to be the saint he was trying to portray at interview two.

The sub-narratives about Duncan's mother and his ex-wife were interwoven throughout the overall narrative yet the heroines in each of the stories were missing from the lived experience as the blue box that stretches the length of the timeline represents. As a result, Duncan felt abandoned yet again; he was lonely and was yearning for someone to confide in. Unfortunately, Duncan and I never got to meet again but I hope he found comfort at the end.

7.2.3 Brian's story

Death of mother and father
Separated from wife

2005 Diagnosed CRC

Diagnosed metastatic disease

Baseline

Hard to see the plot
Story jumbled and incoherent
No context
Suffering from depression

Who is Brian?

Talks about work colleague helping him around the house

Lack of information from professionals

Friendly but quiet
What strategies will I use to stimulate conversation?
TV remained on

Month 6

Awaiting results of scan
Experiencing pain
Opened up – added context, mentioned the death of his mother and father
Described himself as happy

Social isolation - In the end he will be alone

Some health professionals don't seem to care

TV remained on
Shared some context – revealed some of the unsaid

Month 12

Deterioration clear
Cancer spread
Struggling with treatment
Lost weight

Unable to take the treatment which is his only lifeline – Feels like a failure
Visited the Maggie's Centre for the first time. Does he see himself differently?

"you will be alone, whatever"

Feels professionals are not listening
Abandoned and alone

TV quieter but not off
Admits he finds it difficult to talk to people
He wanted feedback *'to see ourselves as others see us'*

Figure 9. **Timeline representing Brian's account of his experience of metastatic colorectal cancer over time**

Brian was 59 years old when the study commenced. He lived alone in what had been his marital home, prior to separating from his wife. As the timeline in figure nine (page 185) illustrates, Brian and I met in his home three times, at six monthly intervals over the course of the year. The specialist nurses who were assisting me with the identification and recruitment for the study encouraged me to approach Brian as they thought he would benefit from having someone to talk to. I instantly saw Brian as a friendly but quiet, shy man and my initial appreciation that Brian was willing to be interviewed was replaced by panic that he might not open up during any of the interviews. My fears were somewhat realised when at the first interview the television remained on for the duration of the interview. When the same happened at interviews two and three, I began to realise that it was not that Brian did not want to talk to me but rather he did not like silence. However, my field notes reminded me that at the third interview Brian reduced the volume on the television, perhaps symbolising that our relationship had evolved.

As the timeline indicates, four years prior to the study Brian had been diagnosed with colorectal cancer. As this was followed by a surgical resection to remove the cancerous area and subsequent chemotherapy he was considered to be cancer free so it was a shock to discover the cancer had returned and metastasised prior to his recruitment into the study. Brian also had diabetes and prostate cancer for which he was receiving hormone treatment intermittently throughout the study. As I have highlighted on the timeline, Brian's narrative from the first interview was incoherent and jumbled insomuch as there were aspects of the overall story which were missing. Moreover, these missing aspects seemed key to being able to make sense of Brian's story. For example, when I asked him to tell me about when he became ill he told me about the original diagnosis of CRC and about the prostate cancer but not about the recurrence or metastases. Consequently, I remember questioning if I had been given the correct information about his condition. However towards the end of interview Brian disclosed his understanding about the outcome of his disease telling me,

"I mean I've been told that it won't get any better, it won't be cured but it's eh it's still (upset) I still can't accept it ken like. It's eh I try not to dwell on it. (Brian, 59 year old male, patient, time 1)

The first interview left me seeking what Brian had left out of his narrative; the unsaid meant the story felt incomplete. Note that there is no orange box relating to T1 at the interview as I failed to gain an understanding of who Brian was. At T2 I tried to make Brian feel comfortable with me, therefore, prior to starting the recorder on the evening of the interview we chatted about his work, his daily routine, my work – we shared an everyday conversation. Brian revealed more during the second interview, disclosing that the last few years of his life had been difficult for him. The excerpt below illustrates what Brian said and the context it added to his overall narrative. What was said in this quote seemed to expose some of the 'unsaid' that I was seeking in the first interview.

"I think I'm happier now, happier and more content. Especially in the last 6 months. Better now than I have been now for a few years since the last 4 years, coming up 5, 4 years say. Since it all began, the cancer, the surgery first of all, well I lost my mum and my dad in the space of 18 months ken that was, and lots of other things that happened as well in between. Breaking up and everything" (Brian, 59 year old male, patient, time 2)

At the time of the third interview Brian's overall condition had deteriorated. Brian told me that the cancer had spread to the lymph nodes and to his lungs and as a result he looked pale, tired and in pain. For the first time since the start of the study he had been prescribed a regimen of chemotherapy but by the third week of the cycle was so violently ill that he could no longer stomach the tablets. Brian was resolute in assuring me that he had tried repeatedly to take the tablets but could not manage it. He seemed gravely concerned that he may be thwarting the only option of treatment and potential lifeline that he had. As I have represented in the orange box on the timeline, Brian did not want to be a failure or a quitter rather he wanted to succeed in being a good patient, who was trying his best. However, his main concern was that without further treatment, he would die. Referring to a consultation with his oncologist, the quote below illustrates this.

"Brian   they'd been asking what I wanted, asking if I wanted to stop *(yeah)*, kind of thing – well no, I don't want to do that……
Emma   what influenced your decision?

Brian   Well, dying, I suppose or like not… I mean, I did try to take the tablets because obviously you want the treatment to be successful" (Brian, 59 year old male, patient, time 3)

Brian spoke little about his relationships at interview one, merely mentioning his sisters and his colleague at work. This led me to wonder if Brian felt alone, which was confirmed in interview two when he described having no-one to talk to and later in the final interview, commented that in the end things change, and ultimately you will be alone.

"That's what was wrong with me just eh not being able to solve any problems and not having anybody to talk to ken about it" (Brian, 59 year old male, patient, time 2)

"you will be alone, whatever" (Brian, 59 year old male, patient, time 2)

Brian had mixed feelings regarding his experiences with health professionals. On the one hand he was grateful to the nurses who took time to listen to him but on the other hand he felt that some health professionals were not listening to him, and he felt he had been abandoned. This, in addition to Brian's self-confessed difficulty talking to people, meant that he often lacked clarity about his condition. This left him feeling frustrated because he craved a clear understanding of what was going on with his body.

At interview three Brian talked about visiting the local Maggie's Centre, as the quote below illustrates. As Brian had confessed that he found it difficult to talk to people I was surprised but encouraged by his visit.

"I do find it sometimes quite difficult kind of talking to people *(mm-hm)* that… ken, if I don't know them *(mm-hm)* or *(yeah)* introducing yourself and "tell me what…" *(yeah)* whatever's up. But I'm glad I went in, ken, they made me very welcome" (Brian, 59 year old male, patient, time 3)

Over the course of the study I saw Brian's willingness to open up evolve and when I asked him how he felt about his participation at the end of the final interview he admitted that it had been good to talk to someone.

7.2.4 Faye's story

Baseline
- Husband died of cancer
- Mother did of cancer
- Cared for them both at home

- Diagnosis 7 months earlier
- Feared the cancer getting worse

WHY ME? Been a good, caring person "I says why me, why me? Cos I just felt no this shouldnae be happening to me"

Role as matriarch dominates - preferred to keep emotions to herself to protect the family

Did not speak of herself as dying Introduced death through sub-narratives about her mother and husband

Month 6
- Lung and liver metastases confirmed

- Uncertainty all consuming
- Dichotomy of wanting to be alone yet wanting to distracted

WHY ME? "But I just wonder why my fate is going to be so nasty and horrible to me because if I was put on a scale in a balance it would be definitely good that I've done for people, not bad."

Identity as the matriarch is affirmed

Feels like she has a death sentence

Month 9
- Tmour liver – weeks to live

- Just weeks to live
- Appears jaundiced and lethargic
- Extreme shock at terminal prognosis

Accepted her fate "what's for you will not pass you" (mm-hm). But he must be needing a special angel up there!"

Faye needs to help her children grieve while she can

Told she has weeks to live – death is imminent

I am shocked by how quickly things can change

Death

Figure 10. Timeline representing Faye's account of her experience of metastatic colorectal cancer over time

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Faye was 55 years old when we met and nine months prior to her recruitment into the study she had been diagnosed with a tumour in her sigmoid colon with accompanying lung and liver metastases. Although she lived alone with her very chatty (and cheeky) parrot[25], Faye had a large family living nearby which included her children and grandchildren who she saw regularly. Faye spoke of her three children and their 'bairns' whom she clearly adored. Faye was one of nine children, and although she spoke fondly of all her siblings, she was particularly close to her sisters, two of whom I met over the course of the study. As the timeline in figure ten (page 189) represents, I met with Faye in her home for three interviews; the first at recruitment, the second at month six and the third at month nine of the study. These interviews were supplemented with monthly telephone calls when I was kept informed of the more day to day goings on and appointments which detailed the medical aspect of Faye's journey[26]. Between the first and second interviews, during one of these phone calls Faye confessed that her condition had deteriorated and a CT scan had showed worsening lung metastases. At the time of the third and final interview Faye was jaundiced in appearance and extremely lethargic. She had been vomiting and feeling unwell in the few weeks prior to the interview and an urgent CT scan showed that the position of the metastatic tumour on her liver meant there was no treatment available to her. Faye was told that she probably only had weeks to live. Her shock at this news is illustrated in the quote to follow.

> Faye   "I went back the week after and I thought the worst-case scenario was I'd have to go on the chemo and they were telling me I've got a few weeks to live *(yeah)*. But that was the worst-case scenario *(yeah)* because I went "oh god, chemo, god…"
> Emma   So that must have been a bit of a shock.
> Faye   It was but I just felt… I can't even tell you how I felt." (Faye, 55 year old female, patient, time 3)

The interview that followed this terrible news focused predominantly on Faye's death and how her family would cope after her passing.

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[25] Faye's parrot could be clearly heard telling Faye to 'stop smoking' during the interview causing much hilarity for Faye, myself and latterly the transcriber.

[26] An in-depth discussion of the telephone calls will be provided in chapter eight.

Faye came from a large family, most of them lived nearby and she saw them with varying degrees of regularity. With three children and several grandchildren there were always people present in the house. Interestingly, at all three interviews a member of Faye's family arrived prior to the end of the interview, as if checking I was causing Faye no harm. Faye expressed that at times the continual presence of her family felt claustrophobic as she did not have time to herself to be at one with her thoughts. She commented that sometimes she just needed some 'me time'. As the timeline shows, at interviews one and two Faye described a dichotomy between wanting to be alone to think about her future, yet fearing the very same – of having too much time to dwell on it. This quote illustrates Faye's dichotomy of wanting to be alone yet wanting to be distracted from thinking about her illness.

> "Emma   So do you find you quite like to be alone with your thoughts as such… or not, do you prefer a distraction?
> Faye   Oh, I do like the distraction but I also would love a wee bit of 'me time' *(mm-hm)*, I've not had any 'me time'. If it's not my family… well, all my kids, it's my nieces and nephews and brothers and sisters and… (laughs) "right, I've had enough!" – "You're awful quiet today Faye" – "no, it's fine, it's just this cold, I just don't feel that great" *(mm)* – I make up lies but it's just that I want to be on my own *(yeah)*. Ken, when the door goes, I go like that: "uhhh!"" (Faye, 55 year old female, patient, time 2)

Faye described at T1 that she resisted discussing her fears with the family in order to protect them, thus preferring to keep it to herself, as the quote below illustrates.

> "Well I've got, there's 9 of us, well I've got 8 brothers and sisters, I've got lots of friends and I've got my own kids. Like all my family, everybody, aunties, cousins, everybody's there. I dinnae have to keep it all to myself but I do because they all relate to one another and there's tom tom drums go cos if I did day something like I wasnae feeling that great" (Faye, 55 year old female, patient, time 1)

At the second interview Faye felt torn as she wanted to be a support to her children and family while she was still able, but she also acknowledged that she needed time by herself to come to terms with what was happening to her. The institution of family and her role as matriarch was central to Faye's account as the orange boxes on the timeline illustrate.

Faye's notable concern at interview three was her family. Faye wanted to spend as much time as she could with her family given that her death was imminent. The quotes to follow highlight how Faye wanted to comfort her children while she was still able to. This emphasised the strength of her identity as the matriarch if the family - being there to comfort her children was seen as an integral facet of motherhood.

> "Faye   The only thing I'm scared of is what I'm leaving behind *(yeah)*, my family, my kids.
> Emma   And again, that's what you've always said, isn't it?
> Faye   Mm-hm. That's all I'm scared… the upset that I can't be there to cuddle them all and tell them it's alright. (Faye, 55 year old female, patient, time 3)

> "when they all {Faye's children} get upset, I get upset but I'm not upset for me, I'm upset for them *(mm-hm)*, really upset for them." (Faye, 55 year old female, patient, time 3)

Faye's position as the matriarch and centre of the family was a thread through all three interviews and her home was the hub for the entire family. Faye described that even as a child she was the centre of the family; literally - she had four older siblings and four younger siblings as she told me with pride at the first interview.

> "We all knew what love was. Ma mother, we knew our mother loved us erm but I just wanted that wee bit extra. I think it's maybe the middle child syndrome cos I'm bang in the middle, 4 above and 4 below." (Faye, 55 year old female, patient, time 1)

At T2 Faye expressed concern about being looked after by her family, as she was used to doing the caring. She told me that she would prefer to be looked after in hospital as she was reluctant to relive the friction that had been caused when she and her siblings were looking after their dying mother.

> "And for being such a big family, like there's nine of us *(mm)* and really it was only four of us that were nursing my mum *(yeah)*. I mean, we were trying to get a break ourselves, it was hellish! (laughs) *(yeah)*. And I'm really not wanting that kind of friction in my own family" (Faye, 55 year old female, patient, time 2)

Thankfully, Faye felt the decision that she would be looked after in her own home was taken out of her hands, as her sisters insisted in looking after her and there was no question that she wanted to stay at home as long as she could. She told me about a discussion she had with her sister about this very topic,

> "And we were talking about that, my sister [name of sister] and I *(mm-hm)* and I says "well, to be honest, I'm not wanting that for anybody" I says "I'd just go into the hospital", she went "you've

not got a choice" *(right)*, she says "I'm sorry Faye, you've not got a choice". Because they're already stepping in, you know what I mean" (Faye, 55 year old female, patient, time 2)

At T1 and T2 Faye questioned 'why me?' She felt that she had been a good, caring person who did not deserve to get cancer, as the quotes below illustrate and the timeline shows.

> "I just thought what have I done? Cos I nursed my husband through it, I nursed my mum, I nursed my dad, I nursed my granny. They didnae die with bowel cancers but I says why me, why me? Cos I just felt no this shouldnae be happening to me" (Faye, 55 year old female, patient, time 1)

> "But I just wonder why my fate is going to be so nasty and horrible to me because if I was put on a scale in a balance it would be definitely good that I've done for people, not bad. So why… why me? *(yeah)* – THAT'S how I feel *(yeah)*. Do you understand that?" (Faye, 55 year old female, patient, time 2)

In light of her terminal prognosis, at T3 Faye described that she had accepted her fate as opposed to questioning why it had happened to her at T1 and T2,

> "I've learnt "oh my god, I HAVE accepted" *(mm-hm)*, I think it's only because of the type of person I am: "what's for you will not pass you" *(mm-hm)*. But he must be needing a special angel up there!" (Faye, 55 year old female, patient, time 3)

At interview one Faye told me about how she had nursed her husband who died of bowel cancer, in addition to looking after her mum when she was dying, and her father and grandmother before they finally had to go into hospital. Faye wanted to establish herself as a beneficent and caring person, but the mention of this was also her way of a) indirectly introducing the notion of death into her overall narrative and b) creating a platform for her to express her fears about her uncertain future. The red boxes which I used to represent how the participants spoke of death, illustrate when death was introduced and how Faye's feelings about her death changed at each interview. Faye did not perceive herself as someone who was dying of a terminal illness at interview one yet she introduced the subject of death when she shared her experiences with her mother, father and husband. In comparison, at T2 Faye commenced the interview by telling me that she felt like she had a death sentence now when she had not done so earlier in the study suggesting that the deterioration in her condition (which is marked in the green

box above the timeline) made the uncertainty that surrounded her situation a little more certain.

Faye's sense of identity as the matriarch of the family was consistent through all three interviews and is the theme which holds her overall narrative together. Faye passed away just a few weeks after the final interview.

7.2.5 John's story

Frames cancer as chronic illness
Understands not curative but not aware of prognosis
On a 'chemo holiday' so no active treatment

Mary wants to open a dialogue with John about his prognosis

Cancer deteriorating – experiencing pain, feels like the tumour is 'bursting out'
Realising limitations
Treatment restarted

Bereavement interview with Mary
Discussed his death

Prognosis 12 to 24 months

Embracing life and independence
Travelling, football match, helicopter ride

Mother died of cancer

20 years earlier diagnosed with heart disease and diabetes

Baseline

Month 6

Month 8

Month 12

Death

Hopes to emulate mother's experience of survivorship

Mary knows that John's experience and their mother's are different

Independent person

Mary worried he was alone

No mention of prognosis, the focus on survival, not death

Striving to remain autonomous.
Having to compromise his social activities but remains hopeful

John gave up at the end
His memory and legacy live on

Comfortable with John – warm and funny
Sister a nurse so shared a common ground

Felt like the beginning of the end

Happy to hear John's memory lived on

Figure 11. Timeline representing John's account of his experience of metastatic colorectal cancer over time

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John was diagnosed with colon cancer and liver metastases 11 months prior to his recruitment into the study. I was introduced to John and his sister (and informal carer) Mary at the clinic and their enthusiasm for the study was obvious. During our initial discussions about the study, John requested that the interviews be conducted separately which Mary agreed to. The first interview was conducted with each, in their respective homes, soon after our introduction and I maintained monthly contact with John by telephone until our second, and sadly last interview six months after the first. I carried out a bereavement interview with Mary, one year after my first interview with her, which was approximately four months after John's death. This allowed me to gather proxy information about the circumstances surrounding his death and hear about how John's memory was being preserved.

John was a warm and funny man whom I felt instantly comfortable with, and charmed by. John started his illness story 20 years earlier when he first started suffering from chronic health problems so as far as he was concerned the cancer was the latest chapter in his story. As the green box on the timeline in figure 11 (page 195) highlights, at the time of the first interview John thought about his cancer as a chronic illness - in a similar way to the angina and the diabetes which he also suffered. Framing the cancer as a chronic illness compared with a terminal illness was integral to John's overall narrative insofar as it legitimised and helped him to fulfil his desire to live life to the fullest (as he had been doing for 20 years), rather than focus on his death. Although John perceived the cancer more as a chronic illness than a terminal one he knew that he would not be cured, as this quote from interview one illustrates.

> "I know I've got chronic cancer that's not going to go away they control it as best they can" (John, 62 year old male, patient, time 1)

At the time of the first interview John was on what he termed a 'chemo holiday' meaning he was half way through a regimen of the second line and more aggressive chemotherapy but it was suspended following admission to hospital with an infection. Mary explained that was she was worried that the 'chemo holiday' was subterfuge by

the medical staff. Mary had initially presumed that further treatment was futile, but she later realised that instead the staff thought John would benefit from feeling well for a while. The quote below, from my first interview with Mary illustrates her concern.

> "So they had given him the option of a chemo holiday *(right)* and I felt "well…" so I wanted to ask about that *(yeah)*, what the implications were, and… Because I wanted to kind of get a sense of "well, was this about withdrawing treatment because it was hopeless *(yeah)* or was the…?" So it wasn't… my understanding was it wasn't really about that, it was about he'd had such a tough time" (Mary, female, sister, informal carer, time 1)

John and I maintained regular contact between T1 and T2 via monthly phone calls which meant I was aware that his tumour blood count had risen, and that the 'chemo holiday' was brought to an abrupt end. Although John expressed his disappointment that he had to restart the chemotherapy, he reasoned that it was far preferable to a premature death. At the time of interview two, John was experiencing abdominal pain, had suffered a fall at home and was having to adapt to his increased frailness. The pain that John was experiencing was his major concern and he thought it meant that the tumour on his liver was bursting out of his abdomen. The quote below highlights how John uses this imagery to illustrate his point.

> "I sort of panicked a wee bit when this thing started in my stomach "oh, so this is it bursting out" like, you know" (John, 62 year old male, patient, time 2)

The timeline highlights that John did not mention his prognosis, nor seemed to have a desire to know about it at interview one, however Mary was keen to open a dialogue about it. One of the most significant things to have been revealed during a phone call between interviews one and two was that John had asked the doctor about his prognosis. John was prompted to ask about his prognosis after watching a film that he found poignant. At the time of interview two I raised the topic of his prognosis in an attempt to further understand why he had asked about it but it was like it had never happened. John preferred to focus on the positive; that he had survived 18 months, rather than how much time he had left. The excerpt below which is taken from interview two illustrates his desire to focus on the positive.

> "John   I'd like to know what the prognosis is *(mm-hm)* but that might be worse knowing, I don't know, you know.

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Emma   Because you did ask about it, didn't you?

John   Oh, I asked about it. I mean, I've survived 18 months *(mm)* plus, because *(yeah)* there's the time before when I had the cancer and I didn't know about it *(yeah exactly, and you didn't know)*. So I mean, I'm 18 months down the line and I didn't think I'd be 18 months down the line to be honest with you." (John, 62 year old male, patient, time 2)

The following quote provides further evidence to suggest that John was reluctant to confront the 12 to 24 month prognosis. Note that at T2 John suggests he could survive ten years although knows it is unlikely.

"if the guy up there turns the page over and your name's on it, there's not much you can do about it *(yeah)*. So I don't know when it is, it could be 10 years from now, I don't know. I doubt it, but." (John, 62 year old male, patient, time 2)

Having said this, at the bereavement interview with Mary shown at month 12 on the timeline, she proposed that John did know he was going to die sooner than he may have alluded to as he had affairs in order. As far as John was concerned, giving up equated to dying which explained his consistently positive outlook and need to embrace life by doing the things he had always wanted to do. In the quote below Mary disclosed that in the end John gave up when the doctors told him there was no further treatment option.

"You know, so he was getting his affairs in order *(mm-hm)* so I think it was still that… he needed to kind of keep that positive thing to keep going *(mm-hm)*. But I think once [name of consultant] had said "there's nothing more we can do for the cancer" I think he's thought "well, that's it then"" (Mary, female, sister, informal carer, bereavement interview)

The death of John and Mary's mother impacted on John's experience. Not only did he live with her for all his adult life but she survived for 16 years after being diagnosed with breast cancer. As the timeline shows, at interview one John was hopeful that the same may happen to him which Mary had also noticed and was a concern to her. John's mother eventually died of metastatic cancer but the fact that she lived for 16 years after the primary diagnosis gave him a prognosis to aspire to. Evidence of Mary's concern can be seen in the quote below.

"he was kind of equating himself to my mum *(mm-hm)*, where my mum had breast cancer and it was like 18 years later *(yeah)* when she got her secondaries. But he was diagnosed with his secondaries *(mm-hm)* at the same time as his primaries *(yeah)* so it was a completely different situation *(yeah)* and obviously a different cancer, so he… And he had other health issues, whereas my mother didn't, so he… And I suppose that's only natural, you kind of look to what experience you've had" (Mary, female, sister, informal carer, time 1)

John was a very independent person and he enjoyed the freedom of not having to answer to anyone. Mary supported John's desire to be independent but she also worried about him, and it upset her that he did not have a spouse or partner to share his thoughts and feelings with. As John's next of kin, Mary felt a greater responsibility to support John as the quote to follow illustrates.

> "if it was one of us, we would have husbands, family, immediate family *(mm-hm)*, you know, I mean kids, whatever *(yeah)*, whereas he doesn't, he just has us *(mm-hm)"* (Mary, female, sister, informal carer, time 1)

However, at interview two John felt his independence was compromised and he described feeling claustrophobic, meaning he was striving to maintain his autonomy, as the timeline shows. At the time of the second interview he was no longer able to travel, he had given up work and his involvement in community youth activities had to stop, and thus his social life was compromised. Despite this he remained hopeful and continued to talk about the things he wanted to do whilst acknowledging the limitations that he was experiencing. It was only at the bereavement interview with Mary that I was alerted to the significance of John's contribution to the youth in the community and what a sacrifice it must have been for him to give it up. However it was encouraging to hear from Mary that his memory lived on and that he had left a legacy behind him[27] – something that so many of the participants wished for.

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[27] At the bereavement interview with Mary she showed me a newspaper clipping of an article that had be written about John and his how his memory was being preserved within the context of his youth activities.

7.2.6 Andrew's story
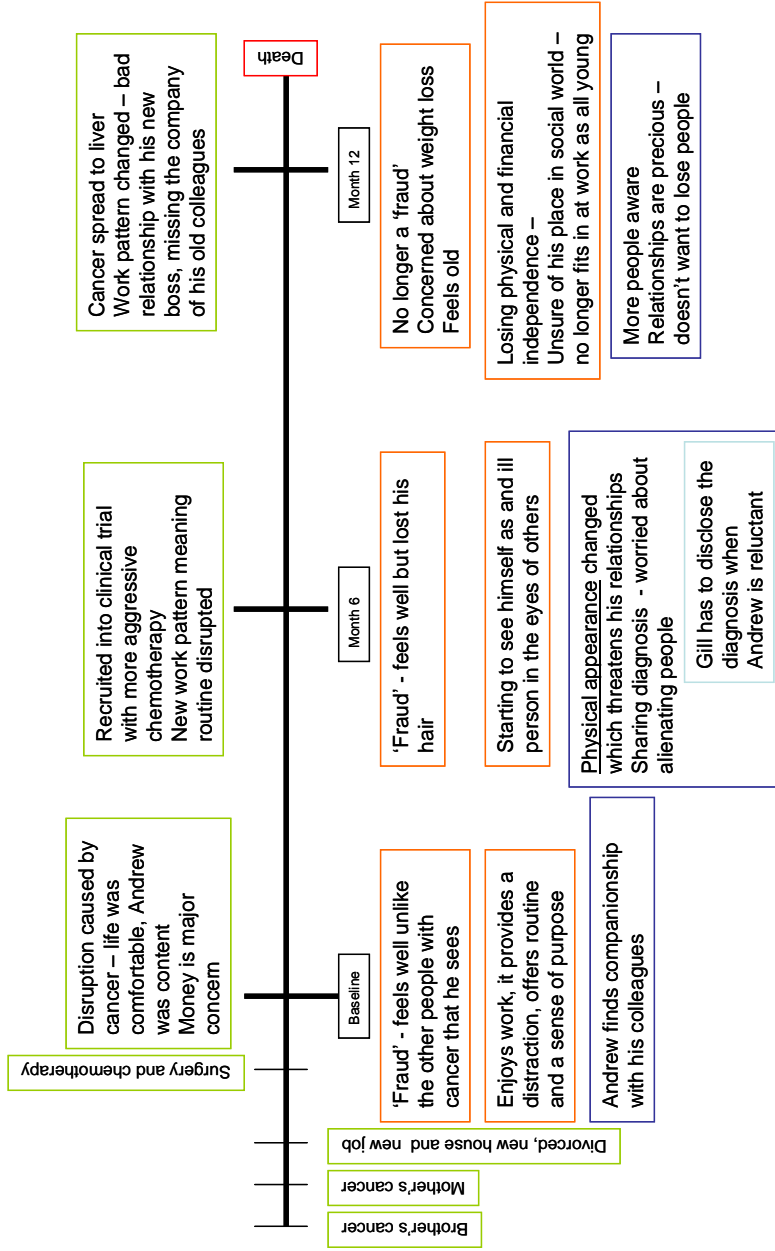
Figure 12. Timeline representing Andrew's account of his experience of metastatic colorectal cancer over time

Brother's cancer

Mother's cancer

Divorced, new house and new job

Surgery and chemotherapy

Baseline

Month 6

Month 12

Death

Disruption caused by cancer – life was comfortable, Andrew was content
Money is major concern

Recruited into clinical trial with more aggressive chemotherapy
New work pattern meaning routine disrupted

Cancer spread to liver
Work pattern changed – bad relationship with his new boss, missing the company of his old colleagues

'Fraud' - feels well unlike the other people with cancer that he sees

Enjoys work, it provides a distraction, offers routine and a sense of purpose

Andrew finds companionship with his colleagues

'Fraud' - feels well but lost his hair

Starting to see himself as and ill person in the eyes of others

Physical appearance changed which threatens his relationships
Sharing diagnosis - worried about alienating people

Gill has to disclose the diagnosis when Andrew is reluctant

No longer a 'fraud'
Concerned about weight loss
Feels old

Losing physical and financial independence –
Unsure of his place in social world – no longer fits in at work as all young

More people aware
Relationships are precious – doesn't want to lose people

Andrew was 57 years of age when he was recruited into the study and had been diagnosed with colon cancer and liver metastases nine months earlier. Although Andrew lived alone, having already separated from his wife, he was well looked after by his three sisters. Gill, one of his sisters was present at the clinic when I first approached Andrew and was recruited to the study as his informal carer. Due to their busy work schedules Andrew and Gill preferred to be interviewed together so three interviews were conducted in Andrew's home at six monthly intervals.

As the timeline in figure 12 (page 200) shows, prior to Andrew's recruitment into the study he had surgery to remove the tumour in his bowel and was subsequently treated with chemotherapy. However, due to a deterioration in his condition between T1 and T2, Andrew had been recruited into a clinical trial with a more aggressive chemotherapy and as a result had lost his hair. At interview three, Gill informed me that a metastatic tumour had been found on Andrew's bile duct and as a result he was receiving a third round of chemotherapy.

Before Andrew was diagnosed with cancer he was enjoying a comfortable and contented life in a new house following his divorce. He had a job which he enjoyed and was feeling generally settled. Andrew had been well until the cancer was diagnosed which seemed to emphasise the disruption it caused. Andrew required emergency surgery as the tumour was blocking his bowel which came as a shock as he had felt well until a few days before. This quote illustrates how the cancer was the turning point when his comfortable, new life which he had built after his divorce changed to a financially challenging and finite one.

> "As I said when, when it all settled down I was fine, I wasnae, there wasnae a problem because (*Yeah*) I'd got the house and everythin else was goin ok until (*Until the*) Until I was taken into hospital. Cos I wasn't toilin for money or anything. I was, I was fine to be honest" (Andrew, 57 year old male, patient, time 1)

Over the course of the study Andrew's illness became increasingly visible to me, and to his friends and family. The timeline shows when Andrew's physical appearance changed - at T2 he had lost his hair and at T3 had lost a considerable amount of weight. At the first interview Andrew described himself as a fraud – this is represented in the orange boxes on

the timeline. Andrew did not feel like he had cancer as he felt well and he viewed himself differently to 'other people' that he saw at the hospital as this quote illustrates.

> "I do feel a bit of a fraud at times *(Yeah)* Because when I go out and see the other people that I think are struggling and I'm saying to myself what are you doin here?" (Andrew, 57 year old male, patient, time 1)

Although Andrew still described himself as a fraud, at interview two he was visibly uncomfortable when we talked about his hair loss. Andrew preferred not to tell people about the cancer as he feared it would alter his relationships as the blue boxes on the timeline, and these quotes from interviews two and three illustrate.

> "Well I think sometimes when people look at you I think, and I'll maybe be wrong here but sometimes when people know that you've sort of got cancer there sort of I don't know if they avoid you or they stand back and go oh ken" *(Andrew,* 57 year old male, patient, time 2)

> **"**I don't like people to feel strange round about me *(yes).* Because some people do *(yeah)*, when you've got cancer *(yeah).* Some people are… it's like "oh!" *(mm)*, so they step back." (Andrew, 57 year old male, patient, time 3)

Andrew's reluctance to disclose his diagnosis to others embarrassed Gill, as it meant that she and the rest of the family had to feed information to friends and family on Andrew's behalf. This created friction between the two siblings and Gill's frustration during the interview was visible. Andrew did not want to be labelled as a victim of cancer, particularly when he was still feeling well, as it hindered Andrew's ability to remain positive. Likewise, if he was unable to work, go to the football or keep his mind active he would be unable to keep a positive outlook.

As the timeline illustrates, prior to the diagnosis of cancer Andrew had been financially and physically independent, but by interview three he was starting to worry that he might not be able to retain such independence. He alluded to not wanting to be dependent on others to look after him, in the event he got sicker, as the quote below shows.

> "I don't want to be in a situation where… [pause] people are having to come and look after me, if you know what I mean" (Andrew, 57 year old male, patient, time 3)

Andrew's financial independence was threatened as he received no state benefits and had to take time off work for chemotherapy which meant he lived in fear of losing his house. Andrew's home represented his independence so, as his sister Gill mentions in the quote

below he was working hard to ensure that he was not going to lose it. Gill was equally worried about the threat of Andrew losing his home and 'haven' but as far as Gill and Andrew were concerned there was little help available to them from a social or financial perspective.

> "he's so determined that, you know "I want to have my house and I want to do this" that it's given him *(yeah)* that spur to keep going." (Gill, carer, time 3)

> "But if you at least know your house is… your 'haven' is safe, if you like *(yeah)*." (Gill, carer, time 3)

Andrew's work situation was a major concern to him at interviews two and three. At T1 Andrew enjoyed his work and it played a significant role in Andrew's life; it kept him busy and offered him companionship. However at T2 his shift pattern was about to change which was going to hinder Andrew's ability to maintain a routine – one of the ways he was able to distract himself from the disruption caused by the cancer. At T3 his shifts had changed and he had a poor relationship with his new boss. Moreover, the time he had to take off and the change in shift patterns had left him in a precarious financial situation. Andrew was unable to move jobs due to his illness, he was unable to re-mortgage because he would not be eligible to get one, and he had no benefits to fall back on. He described the people he worked with as 'youngsters', as he felt they had no understanding of the stresses in his life. There was evidence of a widening cultural divide that was not evident when we first met. As the timeline illustrates, in parallel to Andrew's deteriorating physical condition and changing appearance he was struggling to identify his place in the world, which prior to getting cancer had been obvious to him.

7.3 Part II – Discussion

7.3.1 Overview of the findings

In this section I provide an overview of the findings from the six case histories. I also consider how these findings correspond to the experiences of the group as a whole and how they are situated within the literature.

The six narrative case histories suggest that a diagnosis of CRC causes disruption and restricts the everyday lives of those who suffer from it. Bury's (1982) seminal work on biographical disruption suggests that such disruptions and restrictions result in a loss of identity (Bury, 1982). Bury (1982) defined biographical disruption as the disruption of, taken-for-granted aspects of daily life and the ill person's relationship with the self and with others as a result of the illness (Bury, 1982). However, not all the participants experienced threats to their sense of self as a result of disruption to their daily lives and relationships. The participants in this study can be broadly categorised into one of two groups. Firstly, there were those who experienced disruption which threatened their sense of self over the course of the study. Secondly, there were those that experienced disruption, but did not describe a threat to their sense of self. Furthermore, I noted that biographical work - defined by Bury (1982) as 'the mobilisation of resources, in facing an altered situation' – was carried out in both groups (Bury, 1982). Participants in the former group were attempting to restore a sense of the self, whereas those in the latter group were working to maintain it. I will consider each of these findings in turn.

7.3.1.1 Biographical disruption with a threatened sense of self

Changes to participants' physical appearance and their gradual deterioration over the course of the study sometimes meant they no longer felt like their old selves. For example, there was evidence of physical disruption in Ann's case history which was presented in part I of this chapter. When Ann and I first met she took great pride in her appearance, but her deteriorating physical condition left her feeling old, unfeminine and unattractive. Like

Ann, Brenda described feeling older and assured me at T1 that what I saw that day was not 'her'.

Some participants lost their hair, some experienced weight loss and others weight gain if they had been prescribed steroids. These changes left them feeling less like themselves. Physical disruption was not unique to the females in the study; men also described disruption due to changes in their appearance. For example, I reported above that Andrew lost his hair meaning his illness was visible when it had not been before. He worried about how this would affect his relationships. Chris had always thought of himself as a fit, strong man so his decreasing physical mobility left him feeling unable to undertake his social commitments and his usual role in the house.

However, for the most part the participants described disruption to their relationships, which is perhaps an unsurprising finding given Charmaz's (1983) proposition that 'selves ordinarily are situated in networks of social relationship' (Charmaz, 1983: 176). Disruption to relationships was often linked to physical disruption. Over time, the everyday roles that participants had were threatened and, for some, permanently altered by the illness. I described how Ann's relationship with her husband changed when he adopted the role of being her primary carer. By the end of the study Ann described the stress that both she and her husband were experiencing in their relationship. I also described how Andrew struggled to find his place at work by the end of the study which left him feeling devalued and misunderstood. The experience of cancer had caused disruption, which threatened Ann and Andrew's sense of themselves. Ann struggled to recognise herself and Andrew questioned where and how he fitted into the world. The same could be said for Brenda and Eve who both had to give up work as a result of the cancer.

7.3.1.2 Biographical disruption but no threat to sense of self

In contrast to those whose sense of self was threatened, there were other participants who seemed to maintain their sense of their identity throughout the study. The participants in this group experienced disruption to their common-sense assumptions and behaviours in the

same way as those in the group above described, yet their sense of self remained unthreatened. I identified two possible explanations for this.

7.3.1.2.1 Experiencing hardship

Firstly there were those that described having suffered hardships in their lives. As Faye's case history highlights, she had suffered several losses in her life including the death of her niece, her mother and her husband. Faye had cared for her mother and husband so they could die at home and thus she had first-hand experience of the stresses and strains that this would put upon her own family, when the time of Faye's death came. Faye had a unique perspective when compared with other participants of how her future might look and she felt prepared for what was ahead. Moreover, Faye's experience as a carer herself seemed to affirm her identity as a mother - to Faye, the caregiving role was intrinsic to her role as matriarch. This affirmation was particularly evident in the final interview, just before her death, as the timeline in part I of this chapter highlights.

Similarly, Duncan had experienced loss and abandonment from an early age and viewed the cancer as just another chapter in an otherwise disrupted biography. As I described in Duncan's case history, he spent a prolonged period in hospital as a child when he was diagnosed with TB. Duncan himself acknowledged that his experience as a child had influenced how he coped and explained some of the fears he held. Harry too had suffered loss following the death of his son and although his wife Lily saw Harry differently as a result of his increasing frailty, there was no evidence to suggest he suffered any assaults to his own sense of self.

Faye and Duncan used sub-narratives to emphasise the biographically disruptive events they had experienced, and over time they embedded their experience of cancer within their biographies thus gaining a new insight into the experience of cancer. In this way they were re-interpreting their stories in light of their current situation. For example, Faye introduced the sub-narrative about her husband at interview one but only elaborated on his death at interview two. Thus, over time I gained a greater awareness of how Faye used the sub-

narrative about her husband's death to give meaning to her own experience. In Faye's sub-narrative from T2, she described that although her husband was "lying, dying" he was happy, comfortable, well kempt and surrounded by his family. Faye wanted her family to have the same happy memories that she had following the death of her husband. This again affirmed her identity as a mother who needed to care for her children.

Akin to Faye's story, there were three sub-narratives which abridged both of Duncan's interviews as I detailed in his case history. In the first interview Duncan used the sub-narratives about his mother's death, the break-down of his marriage and the hospitalisation he incurred as a child as a way of introducing his biography, his hardship and his heroines. At interview two he elaborated on how these sub-narratives informed his current experience. For example, he used the story of his mother's death as a way of expressing, as Faye did, how he would like his death to be - with his family around him.

7.3.1.2.2 Living with co-morbidities

In addition to those who described disruptive biographies entailing hardship and loss, there were those with a history of chronic illness. John, Gordon, Fred and Ian suffered other illnesses in addition to cancer. For example, John had suffered from heart disease for 20 years; Gordon had been diagnosed with prostate cancer several years before being diagnosed with CRC; Ian had suffered from Parkinson's disease for many years, and Fred was visibly disabled by COPD. All had suffered restrictions to their lives in the past and had adapted to a new life, and an ill self, prior to getting CRC.

These men had embedded cancer into their lives. This was suggested by the way they narrated their diagnosis stories which I described at the beginning of chapter six. For example, John and Ian both started their diagnosis stories when illness had affected their lives years earlier. For Fred and Harry the story of cancer was more of a small-sub narrative in their overall narratives. As I suggested in chapter six, both Fred and Harry placed greater meaning and significance to the other ailments that they felt affected their everyday lives.

7.3.1.3 Biographical work and mobilising resources

There is evidence to suggest that both groups conducted biographical work. For those whose identity was threatened - the work was attempting to restore their old selves. For those whose identity was unthreatened - the work could be considered as maintenance rather than restoration. Those in the former group seemed to have less success at restoring their identities than those who were maintaining their identities, hence using the phrase 'attempting restoration'. Indeed, over time they seemed to be more restricted by their illness and in the end some of them gave up [28].

7.3.1.3.1 A collective identity

One way that participants mobilised their resources was by assigning themselves a collective identity. This finding came to light through using the VCRM narrative analysis where reading two of the transcript is for how the participant uses the pronouns 'I' and 'you'. Many participants in the study used the pronouns 'I' and 'you' interchangeably during the interviews. At T1 and T2 participants used the 'you' voice to be heard with a collective identity of the cancer patient.

Listening to the 'you' voice allowed me to understand what participants considered biographical work to entail. For example, Deirdre thought that facing up to it was better than getting depressed and crying about it as the quote below illustrates.

> "I mean there's no point in sitting depressed and crying it's not going to get **you** anywhere you're better to face up to it" (Deirdre, 66 year old female, patient, time 1)

This was echoed by Duncan who also reasoned that there were two options following the diagnosis; give in to the illness or live a normal life.

> "after that first few days **you** feel a wee bit sorry for **yourself** and all that shit, you know, then there's only two options *(mm-hm)*: you sit in the house and watch daytime TV and just let the illness get a grip *(yeah)* and **you** just go down all the quicker, I would think anyway *(yeah)*, or **you** try and lead as normal life as possible *(yeah)*, as active as possible" (Duncan, 57 year old male, patient, time 2)

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[28] For an example of this see Ann's case history

Getting on with life seemed to be a common theme within the group. In the quote below Andrew reasoned that there was nothing to be done after he was diagnosed with metastatic disease so 'you've just got to get on and deal with it.'

> "**You** can't do anything about that, it's there, **you've** just got tae get on and deal with it as best you can (*Absolutely)* And ken, if it works, it works. So **you've** got tae get on with it ken" (Andrew, 57 year old male, patient, time 1)

Likewise Brian thought 'you' had to accept that things change.

> "But **you** move on, things change, things never stay the same and **you've** got to get on with things and accept that things do change **you** will be alone, whatever" (Brian, 59 year old male, patient, time 2)

Moreover Brian tried to keep in mind that there were people in a worse predicament than him, as the quote below illustrates.

> "bear in mind that there's other people a lot worse off than **you** are, things are not maybe as bad as **you** actually think they are" (Brian, 59 year old male, patient, time 2)

Finally Duncan thought you just had to battle through,

> "aye, **you** get a wee bit emotional at times but other times **you** just sort of… **you've** just got to battle through it, you know" (Duncan, 57 year old male, patient, time 2)

Interestingly not everyone shared the collective identity and it was not evident to the same extent at T3. For example Gordon and his wife Kate generally referred to 'we' rather than 'you' or 'I' – theirs was a shared experience, so perhaps Gordon did not feel he needed to be part of the collective. Ann only spoke in the 'you' voice a few times at the first interview and it was specific to her talking about the cancer. Interestingly, at interview two, when the cancer was not her primary concern (because the surgical complications were overwhelming) she did not use it at all, which supports the idea that participants feel they have to fit a cancer profile to have this collective identity.

7.3.1.3.2 An after death identity

The participants in this study had been given an incurable diagnosis of metastatic CRC – an aspect that so far seems to be largely absent from the discussion in this chapter. In light of this, I must consider that the difference between those whose identity was threatened and those whose identity was not, could lie with their beliefs about their own mortality. Perhaps

those with other illnesses, in addition to CRC, had considered their mortality at the time they were diagnosed with the earlier problems. Moreover, perhaps those who had experienced hardship, often the death of a loved one, felt they were prepared for death. Having said this, there were similarities in the way that both groups considered their after death identity – another example of biographical work. Participants were concerned with defining their legacy, a theme which became evident at time two and is reported in more detail in chapter six.

7.3.1.4 One size fits all?

Although this discussion may have painted a distinct picture of the two groups; one with threats to their identity and the other without, there were of course some exceptions. The case of Brian illustrates this point. It could be argued that Brian had endured a hard life; he divorced from his wife, his parents died in quick succession; he suffered from a number of other illnesses, yet he suffered threats to his identity as the study progressed. At T3 he felt like a failure as he was unable to endure the chemotherapy which compromised his sense of self.

I have portrayed John as an optimistic, jolly character who retained his identity until he died, but a retrospective account from his sister Mary suggests that this may not have been the case. Mary described that John gave up towards the end which is contrary to his optimistic ideal. Perhaps John wanted to portray a certain identity in this research which highlights the importance of reflecting on the research relationship. I will explore this in more detail in chapter eight.

7.3.2 Situating the findings

In the second part of this discussion I explore how the findings in this chapter relate to the literature. There is a well known body of literature on biographical disruption and identity loss in medical sociology – as I alluded to in chapter two. Bury (1982) argued that in addition to disrupting the physical body, illness disrupts taken-for-granted aspects of daily

life and the ill person's relationship with the self and with others (Bury, 1982). Charmaz (1983) also found that the lives of those with chronic illness were restricted and that such restrictions were amplified because of the unpredictable trajectory that it can take (Charmaz, 1983). Evidence of physical disruption and disruption to relationships were reported by the participants in this study which supports the findings of Bury (1982) and Charmaz (1983).

Charmaz (1983) also found that social isolation and changes to relationships were commonplace which finds support in this PhD study. Social isolation was reported by a number of participants in this study and it was an issue which was exaggerated over the course of the study, particularly as the physical restrictions that participants experienced worsened. Charmaz (1983) also reported that such changes compromised a participant's sense of self (Charmaz, 1983). She described that those with chronic illness may have to give up their jobs, their hobbies and as a result their self image, which resonates with the accounts of Eve and Brenda.

The findings from this study largely support those from a recent study by Hubbard et al (2010) which I introduced in chapter two of this thesis. Hubbard et al's (2010) secondary analysis of the experiences of those with CRC in the first year following diagnosis, also identified that there were individuals whose identity was threatened by the disruption caused by the CRC and those whose identity was not (Hubbard et al., 2010). It was reported in section 7.3.1.2 (page 205) that some participants in this study did not experience threats to their sense of self over the course of the study. Some of these participants suffered co-morbidities in addition to cancer, and others had suffered losses and hardship in their lives.

Bury's (1982) theory of biographical disruption has been subject to criticism in the last three decades, as academics have questioned its applicability to chronic illnesses other than RA. For example, Williams (2000) argued that Bury's (1982) theory of biographical disruption failed to acknowledge how an individual's biography has already been shaped by

the life they have led (for example children who are born with congenital anomalies or who become ill in early life). Thus, the theory of biographical disruption may neglect some illnesses that are biographically embodied in the individual (Williams, 2000). Perhaps the fact that Duncan had spent such a long time in hospital as a child explains why he did not describe a loss to his sense of identity. Likewise Fred, John and Ian had suffered many years of chronic illness which could have been biographically embodied by them over time. Sinding and Wiernikowski (2008) also reported that for some of the women in their study the significance of the cancer receded when compared with the other problems they had (Sinding & Wiernikowski, 2008). This resonates with the Fred's experience of living with COPD and Harry's problems with physical disability and mild memory impairment. The way in which some of these men situated the cancer diagnosis stories within their overall narrative from the first interview, when compared with those of other participants, supports the argument for biographically embodied illness (Williams, 2000).

Pound et al (1998) also found that people who had suffered a stroke and who had previously suffered illness or events which 'had led them to question the foundations and trajectories of their lives' did not describe biographical disruption to the same extent that Bury (1982) had (Pound et al., 1998: 491). This was supported by Faircloth et al (2004) who described that the 'biographical contingencies' of individuals who had suffered hardship meant they did not experience biographical disruption to the same extent as those in Bury's (1982) study (Faircloth et al., 2004: 244).

The findings from this study support the idea that hardship and the presence of co-morbidities may impact the experience of biographical disruption. However, where they differ from Pound et al (1998) and Faircloth at al (2004) is the notion that some illnesses may be seen as a normal part of aging. Interestingly, Dunn et al (2006) reported that some of the older participants in their study saw the CRC as an inevitable part of aging but this is not the same as 'normal' (Dunn et al., 2006). Although CRC did not always result in biographical disruption and was for some, embedded into their lives, neither was it considered to be 'normal' or 'ordinary'. This resonates with the findings of Carricaburru

and Pierret (1995) who researched the experiences of Human Immunodeficiency Virus (HIV) infected men (Carricaburu et al., 1995). Their study comprised of two groups of men with HIV; the first group contracted HIV from homosexual activity and the second from infected blood transfusions which they required for haemophilia. The authors reported that some participants in the haemophiliac group experienced biographical disruption yet others did not. For those who did not experience biographical disruption, neither was the HIV considered a 'normal' illness, as Pound et al (1998) and Faircloth et al (2004) described of stroke. The haemophiliac and the gay participants in Carricaburu and Pierret's (1995) study embarked on 'biographical reinforcement', which Carricaburu and Pierret (1995) define as,

> 'a reinforcement of their identities on the basis of what they had been before the infection' (Carricaburu et al., 1995: 80)

Although biographical reinforcement could be argued in the case of Faye, the concept does not work as an explanatory model for the majority of the participants in this study. I propose two possible explanations why the participants in this study did not seem to view the cancer as a normal part of aging. Firstly, both those whose identity was threatened and those whose identity remained strong undertook biographical work in which they talked about a collective identity. This may suggest that the explanation lies in the cultural attitudes towards cancer. Secondly, all the participants in this study had been given a diagnosis of incurable illness, unlike the participants in Hubbard et al's (2010) study who were in the first year after diagnosis.

Hubbard et al (2010) describe that those who experienced disruption, but no loss to their sense of self undertook the same biographical work as they had done prior to the cancer (Hubbard et al., 2010). I found this to be partially the case in this PhD study, as the participants in both groups undertook biographical work to a) assign themselves a collective identity and b) define their after death identity. By assigning themselves with a collective identity participants alluded to the ways in which the cancer patient *should* conduct biographical work, as I detailed above. The strategies that participants used to normalise their lives were described on a number of occasions as I reported in more detail

in chapter six. Bury (1982) cites normalisation as a way of confronting altered relationships and participant's embarrassment about their illness (Bury, 1982).

Evidence of normalisation strategies was also identified in the CRC literature. For example, Shaha and Cox (2003) found that participants used normalisation strategies to deal with the uncertainty of what lay ahead of them and Sjovall et al (2011) found that in conducting normal behaviours participants were able to reduce the space that the disease consumed in their lives (Shaha et al., 2003; Sjovall et al., 2011). I often heard phrases like 'you just have to face up to it', highlighting that stoicism was also seen to be a form of biographical work. Several participants compared themselves to others, as Charmaz (1983) also noted (Charmaz, 1983).

A number of participants conducted biographical work to define their legacy - an issue that was emphasised over time. This finds support in the work of Exley (1999) who describes how those who were dying used emotional work to limit the 'space' that was taken up by their dying but also to reaffirm their identities (Exley, 1999). This is a similar finding to that of Sjovall et al (2011). This emotional work involved practical tasks like arranging and paying for funerals and making wills but Exley's (1999) participants were also involved in helping their families to grieve, as I described in Faye's case history above. I support Hubbard et al's (2010) argument that, if this kind of emotional work helps participants who are dying to keep a sense of identity through death, it has important implications for patient care in the health care setting.

7.4 Concluding remarks

The aim of this chapter was to consider the process of change at an individualistic level for those with CRC. To do this I presented six longitudinal case histories and gave an overview of the findings for the sample as a whole. The QL design of this study meant I was able to get prospective, retrospective and real time accounts of experience. In this study some participants experienced threats to their sense of self but others did not.

Hitherto, the context in which illness exists in a person's life is important. For example previous hardship and the presence of other illnesses seemed to help some people mobilise their resources in response to the cancer but there were exceptions. I would therefore agree with Williams's (2000) claim, that biographical disruption should not be used as a standardised theoretical framework. Nevertheless it is a useful explanatory device for helping to describe the experiences of those with CRC. Moreover, Williams (2000), Sinding and Wiernikowski (2008) and Hubbard et al (2010) caution on overstating the significance of being older, having a hard life and suffering from chronic illness. This study supports the argument that not all illnesses result in the process of biographical disruption and loss to sense of self for those experiencing it (Pound et al., 1998; Faircloth et al., 2004; Hubbard et al., 2010; Carricaburu et al., 1995).

There are two main ways in which the findings that I have presented in this chapter diverge from those in the literature. Firstly, participants who retained their sense of identity throughout the study did not view their illness as 'normal' or 'ordinary', nor did they see it as an inevitable part of aging, as Dunn et al (2006) suggested. Secondly, the participants in both groups conducted the same types of biographical work in that they considered themselves to have a collective identity and they conducted biographical work to define their after death identity. These differences do not seem to be to the fact that the participants in this study were suffering from cancer, which is both an acute and a chronic illness (Tritter & Calnan, 2002), rather it seems to be because they knew they were dying.

CHAPTER EIGHT
Capturing change

8.1 Introduction

The preceding chapters have illustrated the potential of QL interviewing for understanding the participants' accounts of illness, and have showcased the opportunities for QL analysis. In chapter six, I explored how the accounts of their experiences changed across time, and in chapter seven I examined the process of change at an individualistic level. In this chapter, I move towards a more detailed discussion of the QL method by examining how change is best captured.

This study was designed to explore whether adopting a flexible approach to generating data would allow me to better identify and capture change when it was occurring. The design involved two groups of participants; the first, a six monthly interval group where interviews were conducted at regular intervals and no other contact was made between the waves of data generation. The second, a flexible interval group where the timing of the subsequent interviews were guided by monthly telephone calls. During the telephone calls, participants discussed changes in their situation - if there were any. If there had been a change in the participant's circumstances I requested that we meet for an interview. If no change was identified, the participant defaulted to an interview at month six of the study.

The telephone calls were integral to the flexible approach as they were the vehicle which enabled me to identify and determine change. I conducted telephone calls with each of the participants in the flexible group on a monthly basis (total = 46, see 4.7.3.6). The calls ranged in length from just a few minutes to approximately 40 minutes. The telephone calls were not digitally audio-recorded as I hoped that the informal chats via the telephone, in comparison to the face to face interviews would allow the relationship between me and the participants to flourish (Holt, 2010). Instead I wrote detailed field notes immediately after the telephone calls (see 4.7.4). The participants were aware that the phone calls would be

used as data for the study. Figure five, which was originally presented in chapter five, provides an overview of the chronology of the participant interviews and telephone calls.

As figure five illustrates, there were only two occasions when I interviewed participants early in the flexible group. These were the cases of Eve and Faye. On the basis of this, the findings that are presented in this chapter are due to the regular and intense contact I had with the participants in the flexible group, as opposed to the timing of the interviews I had with them. I reflect on my reasons for interviewing Faye and Eve early, later in this chapter and also consider the incidences when I could have interviewed participants but why I did not.
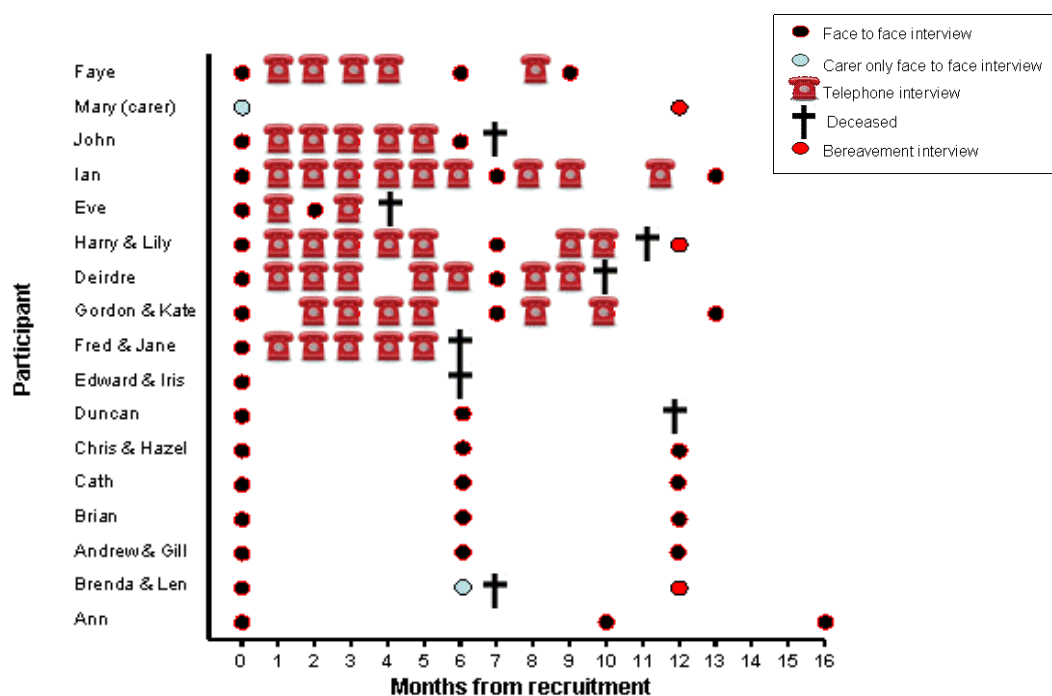
Figure 5. Chronology of participant interviews, telephone calls and deaths

In part I of this chapter I examine the benefits and challenges of the using a flexible approach for generating data, when compared with that of the routine approach. In comparison to the preceding chapters, this chapter will be more reflective in nature, albeit my reflections are supported by excerpts from my field notes and from the interviews. In

part II, I conclude this chapter with a discussion about the overall value of the flexible approach to interviewing and when it may be justified.

8.2 Part I – Benefits and challenges

I will compare and contrast two case studies to illustrate the benefits and constraints of flexible approach to generating data. Cath, a participant from the six monthly interval group and Deirdre from the flexible interval group. These women shared similarities in terms of their physical condition and in their home life, yet their accounts of illness were very different. This encouraged me to question the extent, if any, that this was due to the research process and my relationship with them. My reflections will be supported by my experiences with other participants in the flexible group. Figures 13 and 14 represent the chronology of the interviews and telephone calls with each participant and the corresponding themes from each time point. The boxes in black indicate the themes which arose at each time point from the face to face interviews. The boxes in green indicate the **issues that were discussed during the telephone calls with Deirdre**. The red boxes indicate **the issues we discussed that I felt contributed to the overall development of my relationship with the participants**.

Cath was 48 years at the time of recruitment and she had been diagnosed with CRC and accompanying liver and peritoneal metastases 15 months prior to her recruitment into the study. Since the diagnosis of CRC, Cath had also been found to have uterine metastases for which she had a hysterectomy, meaning she also faced an early menopause. Cath lived with her two adolescent children and received physical and emotional support from her mother and siblings. I carried out two formal interviews at Cath's home and one informal face to face interview with Cath at the hospice. Although I had intended to record the third interview with Cath, when I arrived and saw how frail and weak she was we decided, in consultation that it was appropriate to restrict our meeting to just a short chat. I confirmed prior to my meeting with Cath at the hospice that the medical staff were happy with the situation. I wrote detailed field notes immediately after my visit to the hospice, and before

leaving, confirmed that Cath was happy for me to use these field notes as data. Therefore, figure 13 (page 220) highlights the themes from each time point including this final meeting in the hospice.

Deirdre was 66 years old when the study commenced and like Cath, she was suffering from extensive disease. She was diagnosed with CRC and metastases in her cervix, vagina and latterly on her head. Deirdre lived with her husband and had two grown up children and several grandchildren. Deirdre was incredibly proud of her children and spoke of them often over the course of the study. Deirdre and I met face to face on two occasions and spoke on the telephone at monthly intervals, before her death at month ten of the study.

In terms of their similarities; both Cath and Deirdre had extensive disease and both had been told that the cancer was incurable. They both had children, and a loving and supportive extended family around them. Both enjoyed socialising and valued the company of their friends in order to feel normal. Despite these similarities, the narratives they told were very different. The thread through Cath's narrative was her focus on survival, as I have indicated in figure 13 (page 220). However, unlike Cath, figure 14 (page 221) highlights that Deirdre voiced at the first interview that her prognosis was in months; "not days, weeks or years" and during the interview she used the words 'terminal' and 'palliative.' This declaration at interview one suggested to me that Deirdre was comfortable talking about her death. Her blatant acknowledgement of her status set the scene for the remainder of the telephone calls and interviews.

Although Deirdre and Cath started their narratives in different contexts - one with a focus on survival and one with a clear prognosis – their respective illnesses took a similar trajectory which enables an interesting comparison of the flexible approach with the routine, six monthly approach.

Baseline

Not an easy interview. This could reflect my feelings about her being the youngest in the group with young children.

FOCUS IS ON SURVIVAL
Copes by acting normally

Does not want to feel sorry for herself

Does not want to be perceived as a cancer victim

Highlighted the potential for information overload

Felt isolated as she was unsure of who to contact in case of an emergency

Tried to keep in good physical condition

Month 6

Unable to talk about Cath's future while she was focused on surviving.

FOCUS IS ON TREATMENT – NOT GIVING UP
Worried about her children – she tried to shield them for the cancer but was no longer possible

Feels like a burden to her mother
Tries to stay positive

Keeps herself busy but unable to forget

Month 12

I still felt unable to ask Cath about her future, despite her proximity to death

STILL CONSIDERING TREATMENT OPTIONS .
Been searching the internet for other treatment options

Few treatment options remaining

Her stay in the hospice gives her mum a break

No mention of her future and her proximity to death

Figure 13. Chronology of interviews with the corresponding themes for Cath

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Timeline nodes: Baseline — 1 — 2 — 3 — 4 — Month 6 — 5 — 6 — Death

Month 10 – informed that Deirdre had passed away by the specialist nurses

Baseline
- Husband present so guarded.

Node 1
- Spoke of her recent holiday and her son's impending visit

- QoL decreasing. Due for more chemo. Going to have lunch with her girlfriends

Node 2
- Going on holiday. Spoke about her son's job and his girlfriend. Very proud

- Having daily radiotherapy. Feels better as something is being done.

Node 3
- Told me about her daughter who had recently graduated. Now on first name terms

- Radiotherapy finished

- Deirdre seemed pleased to see me

Quick chat as we bumped into each other at the hospital

Node 4
- In hospital from side effects of chemo. Shaved her hair off, now wearing a wig. "the inevitable has happened" – metastasis in her head. Will refuse further chemo if the side effects are as severe as the next time. Unable to socialise

- Confided in me that she worried about her husband's ability to cope

- In pain, sounded tired. Treatment discontinued. Reiterated that she does not want the family making decisions for her.

Node 5
- Husband was asleep on the sofa which was my signal that she would not be talking about sensitive issues

Node 6
- No energy. Sleeping in the living room. I had planned to phone again in 2 weeks

- Deirdre just wanted to spend time with her family.

Themes box:
- Extremely shocked when asked whether she wanted to be resuscitated in the event of a significant decline in her condition
- Thinking about discontinuing treatment
- Striving to maintain autonomy
- Does not want to leave a negative emotional legacy with her family
- Tries not to think about the cancer but it is omnipresent
- Fears being in pain

Baseline themes box:
- *"won't be days, won't be weeks, won't be years"*
- Wants to continue living her life but it is difficult to make plans
- Being depressed doesn't get you anywhere – have to have a laugh
- Had to think of the future and make out a will
- Likes to understand her illness and the treatment
- Concerned about losing weight as it's a physical sign of her deterioration
- Acknowledged a change in the culture of cancer. Compared to her mother's generation it is freely discussed and common
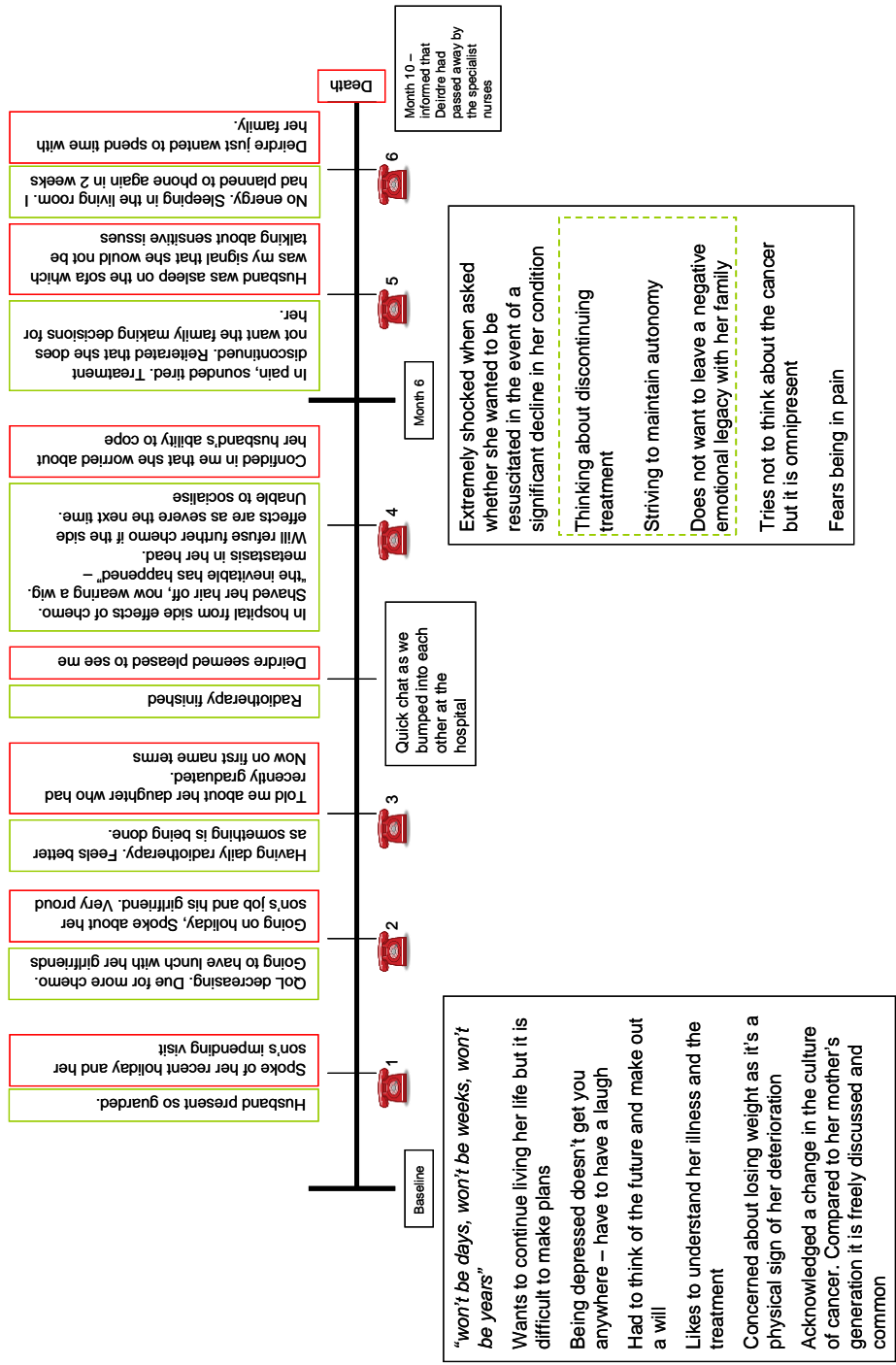
Figure 14. Chronology of interviews and telephone calls with the corresponding themes for Deirdre

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8.2.1 Benefits of the flexible approach to interviewing

In this section I consider the benefits of the flexible approach to interviewing.

8.2.1.1 Adding context to the narrative

The data which were gathered from the telephone calls added contextual information to the accounts of those in the flexible group. The green boxes on Deirdre's timeline illustrate how the regular contact allowed me to gain a real-time sense of how her illness was progressing and what treatment she was receiving, or not receiving as a result. I was able to map the 'ups and downs' which participants saw as a characteristic of the illness experience in chapter six (6.2.1.2.1). For example, Deirdre seemed brighter at TC3 despite the rigorous and tiring regimen of daily radiotherapy because she saw the treatment as a positive action towards improving her discomfort.

As part of the longitudinal analysis, I also explored how the contextual aspects of the story changed over time. For example, Deirdre ceased discussing her friends or talking about social outings during our telephone calls, as the green boxes on figure 14 (page 221) indicate. In fact, she did not seem to be socialising much at all; an activity she had previously enjoyed. Accordingly, when we met face to face I probed further into this issue and she told me that she had not seen her friends for some time. In this way, the telephone calls informed subsequent interviews as well as adding context to the narrative.

During the interviews and telephone calls, Deidre spoke at length about her family, as the red boxes in figure 14 (page 221) show. Through the telephone calls, the personas of her family were kept alive and Deirdre was giving me access to the part of her life where her identity was not as a cancer victim but as a mother, a grandmother, a wife and a friend. By the end of the study I had heard so much about Deirdre's children, and seen photographs of them that I felt I knew them myself. In contrast, Cath spoke little of her family or friends as figure 13 (page 220) illustrates. This meant I had little impression of

the world that existed outside the room where the interviews were conducted. Interestingly, both women described a keen sense of having to protect their loved ones in light of their deteriorating condition. Although I knew that this was important to Cath I did not understand the process she took to vocalising her need to protect – the why and the how. In comparison, I was able to track Deirdre's experience and her rationale for wanting to protect her family via the telephone calls and witness it in real time. I expand upon the idea of tracking experiences in the section to follow.

I gathered useful contextual information on all the participants in the flexible interview group. For example, Fred shared that he and his wife Jane had decided to take a day trip for some respite. This was something that they had enjoyed before Fred became ill and it suggested to me that he was striving to maintain some aspects of his normal lifestyle. Likewise, Gordon always mentioned if he had been out playing golf or had visited his holiday home. John told me he had given up his much-loved hobby during our third telephone call; a longstanding pastime that he had enjoyed for decades. I asked John to reflect on his feelings about this at interview two and whether it had affected his quality of life – which he reported it had not. This is another example of how the telephone calls informed the later interviews.

8.2.1.2 Capturing change as it happens

In addition to supplementing the contextual information of the overall narrative the regular contact enabled me to witness some critical moments in the participants' experiences. As I have illustrated in figure 14 (page 221), during TC4 Deirdre informed me that she would discontinue chemotherapy if she suffered the same hideous side effects that had resulted in an earlier hospitalisation. At the time of her telling this, I was unsure of the significance of it within her overall narrative so I probed into the issue further when we met a month later. The longitudinal analysis of Deirdre's case study highlighted that her thoughts about discontinuing treatment signified her strive for independence. In the dashed green box on figure 14 (page 221), I have highlighted the relationship between what was said at our chat at TC4, and the themes which arose at

interview two. Through exploring Deirdre's desire to maintain autonomy, she was able to express her expectations about how the disease would progress and her worries about being in pain.

I was able to track the process of change that Deirdre was undergoing, in order to gain a greater understanding of her rationale for wanting to protect her family, which is in contrast to Cath. During interview two, Deirdre was able to express her fears about her family, and how she did not want them to be wounded by the decisions they felt they had to make on her behalf. In this way she was negotiating her after death identity in the same way as Faye did in chapter seven. Deirdre, like Faye was ensuring that her reigning identity was that of a mother, not as a victim of cancer.

Like Deirdre, John described what I perceived to be a significant change between interviews one and two. Below is an excerpt from my field notes that were written immediately after the second telephone call with John.

> *John has had what he described as a strange week. He watched a film about two men, both with cancer, who met in hospital and decided to write a list of things they wanted to do before they died. John found the movie really poignant, and for him it was the impetus to ask about his prognosis when he went to clinic yesterday. Both Mary (John's sister) and John had told me that they hadn't yet inquired about this (at interview 1) let alone talk about the future and what may happen. I think he had been building up to this for some time and the film was the catalyst. So he asked the [doctor] yesterday about how long he had left and was told it would probably be months rather than years but could even be 12 – 24 months. I asked him how he felt about this and he sounded ok and that he really didn't have any idea how long it would be so in a way it was a relief to know. Knowing this information also made him think about the things he wants to do before his death; he wants to visit Dublin to do some more work on his family tree and go to London to catch a show and watch a football game with his nephew. (Field notes, TC2 with John)*

As my field notes indicate, John had not asked about his prognosis at interview one. Indeed Mary, John's sister, confided to me that John had thought he must have at least a year to live because I had asked him to participate in this longitudinal study. This suggests he had previously considered his prognosis, therefore, I saw the fact that he had enquired about it at month two as a significant event, which had possible consequences for his life. Despite my speculation of the significance of John's enquiry about his prognosis, John did not mention it at interview two. I am unsure as to whether John

would have mentioned his prognosis to me at all at interview two had I not probed him about the subject. Perhaps he wanted to forget about it; intent on seeking the positive rather than how much time he had left. Or, perhaps the use of the telephone offered him a degree of anonymity.

During my bereavement interview with Mary she confirmed that my instinct about the significance of John inquiring about his prognosis was right. As the quote below shows, as far as Mary was concerned John 'hung his hat' on the prognosis he told me about during TC2.

> "And he did ask one of the doctors and she says "well, I think we're talking months rather than years" *(mm-hm)* but then she said "24 months" and I thought "well, that's two years so why…!" *(laughs)* So he kind of hung his hat on that" (Mary, female, sister and carer, time 3, bereavement interview)

Furthermore, Mary described that when he asked about his prognosis she was able to open a dialogue about John's wishes for his death – something that Mary had been hoping to do for some time, as she described at interview one. The quotes below from interview one, and my bereavement interview with Mary illustrate the change that happened over the course of the study. In the first quote from the T1 interview, Mary is speculating about when might be a good time to raise the issue of John's death with him. In the second quote from T2, she tells me about when she did eventually raise the issue with him after he had asked about his prognosis – thus for John and for Mary this was a turning point.

> "So I have wondered about that [asking about John's wishes for the future] and I'm just kind of waiting for the right opportunity *(mm-hm)* and I'll know it when I… *(yeah)*, I'll know it when it's there he's not going to survive this condition in the longer term but he's… you know, I think he's… I've been waiting till he's more kind of up on his feet *(mm-hm)* and physically a bit better *(yeah)*, then I'll feel like I can *(That's understandable)* I'll try and do a bit more kind of "do you want to go out for lunch", it's the chat, kind of thing" (Mary, female, sister and carer, time 1)

> "he'd seen this film – it's Morgan Freeman or whatever *(yeah)* – and it obviously struck a chord with him *(mm-hm)* and he thought "oh, that's something I'd like to do *(mm-hm)*….I mentioned that to him and I said "have you given any thought to…?" – it just kind of flowed naturally into the conversation, and he said "well, yeah, a bit" you know and that's when we got onto about "so would you like to, when the time comes, when you're poorly and whatever, what would you like to happen, do you want to stay at home?" and he said "oh no, I'll go into the hospice" and I said "well, we could look after you because we could… we've discussed it (Mary, female, sister and carer, bereavement interview)

I have illustrated how the telephone calls worked well to identify change for John and Deirdre but this was not always the case, as my experience with Fred indicates. I spoke with Fred every month, generally when his wife Jane was at work. Unfortunately, I did not meet with Fred for a second interview because he died suddenly after suffering a fall. When I spoke with Jane (an extremely difficult conversation which I will expand upon later this chapter) she told me that Fred had been diagnosed with brain metastases in addition to lung metastases; something which Fred had never mentioned. This emphasises that even though I was maintaining regular contact with Fred, and felt we had a good relationship, there were still things that he did not want to share. I was unable to explore why Fred omitted this information, so can only speculate about potential reasons for his silence. It could reflect a gap in Fred's knowledge, perhaps he was unaware of the presence or significance of the brain metastases; perhaps Fred was in denial that he had been given this terminal diagnosis, or perhaps he did not want to share this information because he feared upsetting me, himself or more likely, Jane. I will explore these issues as potential limitations of the QL design in chapter nine.

Owing to the flexible approach, and the contextual data that the participants divulged during the telephone calls, I was able to uncover what changes could trigger an interview. Following each telephone call I reviewed the conversation and considered whether any critical events had occurred. When there was not, I considered if there were any precursors to change that might trigger an early interview. Interestingly, my field notes suggested that the potential events that could trigger an interview were broadly categorised as social aspects of the illness experience. For example, Ian feared not being able to attend his weekly dance classes or being able to converse and have a laugh with his friends. In addition to singing in a choir, Eve played and taught the guitar, both of which she eventually had to give up. Music had always been a part of Eve's life and without it she may have felt her identity was compromised. Likewise, John informed me about having to give up a hobby which he had enjoyed for decades. Mary emphasised the significance of John's hobby during our bereavement interview, as I detailed in his case study in chapter seven (page 195). This is consistent with the

findings presented in chapter seven about the disruption of relationships and the resulting social isolation that some participants experienced.

Interestingly, what *could* trigger an interview was not what *did* trigger the early interviews that I conducted with Faye and with Eve. The reality is that when I did interview two participants early it was because they had experienced a physical deterioration. For example, Eve was told just two months after the first interview that she would require a course of the more aggressive chemotherapy and that she had been referred to the hospice for pain control. I was keen to capture this transition to hospice care so we met for an interview. As Eve's deterioration occurred so quickly after the initial interview, and her death quickly after the second interview, I reflected that it was the right decision to interview her when I did. Similarly, Faye told me that she had been given a few weeks to live at month nine of the study, as I detailed in her case study in chapter seven.

Why did I privilege the physical aspect? Firstly, as the data collection phase of the study progressed, the interviews seemed to parallel the participants' clinic appointments. It was at these clinic appointments that the participants learnt of a change in their condition and where the likely physical changes would trigger an interview would become apparent, hence privileging the physical. However, I also found that the telephone calls served as a de-briefing session for those who had just attended the clinic; an opportunity for them to recount what had happened and for them to process it - another benefit of the more intense contact. In addition, aligning the telephone calls with the clinic appointments also seemed to legitimise the interaction between the participant and myself by giving the participants a reason to chat to me – moreover, perhaps the telephone calls were easier if they felt they had more to say.

The second reason for privileging the physical was that participants may have only told me what they thought was important at the time or what they thought I wanted to hear. The participants tended to focus upon the medical aspects of their illness; as was the

norm for them in medical consultations. This may also be a reflection of the culture in which the study was being conducted; I recruited in a hospital and was a nurse, so perhaps there was an assumption, particularly at the beginning of the study that I wanted to hear the medical story. Thirdly, the longitudinal analysis of the transcripts and field notes suggests that the significance of the threats to identity that the participants spoke of were cumulative, thus were emphasised over time. This meant that it was not always possible to identify psychological and social decline prospectively. For example, it was when Gordon told me for the third time that he was happy to back playing golf again that I understood the significance of this activity. Gordon was able to be back to his normal, pre-cancer activities which thrilled him.

8.2.1.3 Relationship and reciprocity

In this section I share my personal reflections on how my relationship developed with the participants in the flexible interval group, when compared with the six monthly group. As figure 14 (page 221) suggests, there are many more red boxes on Deirdre's timeline than there are on Cath's, which is due to the regular contact we maintained. My relationship with Deirdre evolved in parallel with our telephone calls, and by TC3 Deirdre had asked me to call her by her first name. As Deirdre and I got to know each other better she started asking me more about my family – where was I from? Was I married? Did I have children? How was the thesis going? Deirdre expressed a genuine interest in my circumstances and it highlighted the importance of reciprocity in our relationship. In this case my role was interchangeable; moving from researcher to confidante. Although I think this was a positive thing there were challenges which I examine later in this chapter.

Like Deirdre, Faye also shared an interest in how things were going. We often talked about her family and how her grandchildren were growing up so fast, and she reciprocated by asking about me. Faye and I spoke monthly during the six months between interviews one and two. We shared lengthy chats where she told me about her family and friends, in addition to her worries about cancer. At the second face to face

interview with Faye she immediately told me that she felt she now had a death sentence which represented a significant change given that she had not considered herself as someone who was dying at T1[29]. Not only did this alert me to the fact that she had been thinking about our interaction in the interim period, but also that she could omit the usual 'cancer story' that I detailed in chapter six. This was the well rehearsed, public narrative that was told at the beginning of interview two where participants updated me on how the cancer was progressing, what treatment (if any) they were receiving and any immediate problems they had. The fact that Faye replaced the usual public cancer story with her fears that her life would soon be over suggests that she felt at ease from the outset of interview two. Consequently, she seemed content in delivering the private account more readily than others.

In describing Faye's case I do not wish to imply that those in the routine group did not elicit private accounts. Rather they told the cancer story, as did most of the flexible group, before sharing their private accounts, as if preparing themselves. Having said this, I sometimes felt like I was unable to elicit any more than the public account. For example, in the case of Brian, I commented in my field notes that I felt I had only heard the public account of his experience, as I merely heard snippets of the private account. Thus, Deirdre and Faye were fairly unique, which could be the result of good rapport and a reciprocal relationship that we developed over the ten or so months they were in the study.

Although I gained contextual information and sometimes captured real time transitions in the lives of participants in the flexible group, this could have been the result of reasons other than the increased contact and more evolved relationship I shared with them. For example, some participants were naturally chatty, particularly the females. Moreover, I seemed to share an affinity with the females in the group, likewise them with me, which could have impacted upon what the participants were willing to share

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[29] Details of Faye's case study, including quotes can be found in Chapter seven of this thesis.

with me. I felt as if I only heard a public account from Brian and interestingly he mentioned to me that I should not be doing this kind of work. Brian thought it would be too upsetting, which may be a reflection of my age or my gender. With this in mind, perhaps other participants could have omitted sensitive issues from their seemingly private account. I consider this issue as a limitation of the study in chapter nine.

I gained little information from my interviews with Cath concerning her wishes for the future, which is in contrast to Deirdre. Perhaps Cath was a private person who felt uncomfortable talking with someone she did not know. However, the fact that Cath's story of survival remained unchanged when we met at T3, when it could be argued that we knew each other better, illustrates the strength of her desire to believe she would survive. There were glimpses that she had thought about how her future might look as this quote from interview one suggests, but on the whole Cath's silence suggests an inner struggle.

> "You know sometimes you're lying in bed at night and you think oh God what's my future?" (Cath, 48 year old female, patient, time 1)

I am doubtful that Cath would have shared a private account at all, as at the time of our meeting her rhetoric was about survival; there was no place for negativity. Having said this, I must also confront the possibility that my own fears may have obstructed my ability to probe Cath in such a way as to allow her to discuss her death. Perhaps this is a reflection of my own discomfort about interviewing a relatively young participant, with young children, who was dying. Consequently, without the added context, and the development of our relationship through the monthly telephone calls, I felt unequipped to raise the same sensitive topics that I had with Deirdre, Faye or John.

8.2.2 Challenges of the flexible approach to interviewing

8.2.2.1 Balancing ethical integrity and research integrity

I faced ethical dilemmas whilst generating the data for the flexible interval group which did not occur in the six monthly group. In the section to follow I will detail these

challenges and how I dealt with them. For some participants, the telephone calls seemed to be a positive, even enjoyable interaction but I worried that for others they may have been considered an intrusion. For example, Gordon was always busy playing golf with his friends and although he was always extremely polite, I worried that he may have considered the calls an intrusion – a distraction whilst he was conducting his biographical work to get back to normal. Likewise, Fred's wife Jane was often reluctant to talk on the telephone and I was concerned that my regular contact reminded her of Fred's fragile existence.

8.2.2.1.1 Valuing the participant's right to privacy

During the study there were times when I felt that conducting a face to face interview was not appropriate, even when a significant change had occurred which would have otherwise triggered an early interview. For example, during our penultimate telephone call, Deirdre informed me that the health care team had decided to discontinue treatment. I knew, as did Deirdre, that this was not a good sign and that her life was probably coming to end. Accordingly, I respected Deirdre's priority to be with her family despite the fact that the decision to discontinue treatment was something we had been discussing for several months. Below is an extract from my field notes after the penultimate telephone call with Deirdre.

> *Although I knew it may be valuable to interview Deirdre now I also knew that she should be spending more time with her family in her final weeks/months......I was also sad at the thought that she doesn't have long left yet she was still asking about my Xmas and New Year. Amazing how people can still function within these social norms at times like this. (Field notes from TC 6 with Deirdre)*

Likewise, John was admitted to hospital with a bad infection at month three of the study and when he returned home he was weak, vulnerable to further infection and down beat. Although I may otherwise have chosen to interview John at this time, his focus was on his sister's imminent arrival from abroad. John had not seen his sister since his diagnosis and thus I decided to postpone the interview until his sister had returned home.

Needless to say the same ethical considerations were given to those in the six monthly interval group, as I illustrated earlier in this chapter with the case of Cath. I described that my third interview with Cath was an informal chat rather than a recorded interview because of her frail and weak state. I was able to observe Cath's weakness and the pain she was in, but in the examples of Deirdre and John above I could only hear the stories. Without this visual portrayal I had to scrutinise what was being said, or more accurately perhaps, what was not being said.

I propose that the participants would have willingly participated in an interview had I asked, which may be explained by the more evolved relationship I had with participants in the flexible group where they felt more of an investment in the study and more of a responsibility to me. It could be argued that by deciding to not to interview the participants I was taking the power to make decisions out of their hands. Given the good relationship I had with the John and Deirdre perhaps I should have been able to ask them about participating in an interview in such a way that would have allowed them to say no. However, I believe that doing so would have threatened our relationship and as I hope to have illustrated, my foremost concern was to retain the ethical integrity of the study.

8.2.2.1.2 The unpredictability of research

In chapter four (page 72) I detailed the ethical process which I conducted prior to the start of the study. Although I adhered to the request of the ethics committee that I check the status (alive or deceased) of the patient before making any telephone calls I was faced with two personally challenging incidents involving the family members of two participants from the flexible interval group. The first was with Eve's daughter, who was not recruited as an informal carer in the study, although Eve had mentioned her on numerous occasions. The extract below from my field notes details what happened.

> *For the last 2 weeks I have been trying to contact Eve and was starting to get quite concerned. She regularly house sat for people so I thought that was probably the case. I thought I would try one last time this afternoon and perhaps it was meant to be or something because her daughter answered the phone. Unfortunately Eve passed away.*

She was admitted {to the hospice} and deteriorated extremely quickly. She died after vomiting blood and she became unconscious. Her daughter was told to come in but was called 10 minutes later to hear that her mum had died. [Daughter] mentioned that her mum had been experiencing abdominal pain for the few weeks preceding the admission and the last time we spoke she had been referred to palliative care…….. I think I handled the situation in the best way I could given that I was so shocked. I allowed her daughter to tell me the story without commenting and offered some kind words about her mum at the end. All in all an extremely difficult and upsetting situation…….Although I knew Eve was ill I did not expect her to deteriorate so fast. She was looking forward to hearing about my holiday to India as it was somewhere she had always wanted to go….. I also feel for her daughter who was there today to clear out her stuff. She is the same age as me and is getting married soon. Eve had hoped to be at the wedding and it is tragic that she won't make it. Her daughter sounded so strong on the phone. I felt terrible that she was there….. I apologised for catching her like that and she was very nice about it. I told her that I was very fond of her mum and I would be thinking about her and the rest of the family. (Field notes from TC4 with Eve's daughter)

Within a few months of the phone call with Eve's daughter a similar situation arose in the case of Fred. I chatted with Fred regularly and as it happened Jane, Fred's wife was often at work when I called. Moreover, Fred usually answered the telephone as it was beside his chair in the living room. Therefore, I knew something was wrong when Jane answered. She tearfully explained that Fred had passed away peacefully just days earlier. Jane spoke candidly about the circumstances of his death and expressed her grief at his passing. Indeed, she told me that she had been looking for my number so she could call and inform me about what had happened. I offered to come and speak with Jane but she declined, on the basis that she needed time to grieve. My field notes remind me of my initial thoughts after the call,

I was upset for Jane and I did cry on the telephone with her when she did. They were such a nice couple who were obviously quite private people yet they welcomed me into their home. I was really touched that they had enjoyed the process. Jane even described how nice Fred thought it was that I was taking an interest in him…..Overall they enjoyed participating in the study. I am constantly surprised at how thoughtful people can be even after a death. Jane had been looking for the number to call me when I called her. (Field notes after TC6 with Jane, Fred's wife)

The two examples above were unique to the flexible group and were a result of the increased contact with those participants. I usually heard about the passing of those in the six monthly interval group from the specialist nurses at the recruiting centre, at which time I sent a sympathy card to their carer if they had been recruited. The cases of Eve and Fred highlight the complexity and unpredictability of researching the

experiences of people with serious illness, where circumstance change quickly. The outcome of these telephone calls was due to unfortunate timing, and they happened because of limitations in information sharing between health systems and the researcher. Nevertheless, this is the current reality of research. It is unpredictable, and I can only trust that I handled the situation with the necessary sensitivity.

8.2.2.2 Blurred boundaries

Over the course of the study I shared long, and sometimes profound telephone conversations with a number of the participants in the group, as the aforementioned findings indicate. This meant that the boundaries of my role as the researcher became blurred. In the final section of chapter four I discussed how I brought different selves to this research project and these different selves became most apparent to those in the flexible interval group. Although I anticipated what I would bring to the project, I had not anticipated how participants would perceive my role - researcher, nurse, and confidante - and how this would change. To follow are examples from two of the participants to illustrate this.

First is the case of Deirdre. Throughout this chapter I have referred many times to my interactions with Deirdre and this is because we shared lengthy conversations and had a reciprocal relationship. In chapter six (6.2.2.2, page 143) I described that Deirdre did not want to leave a negative emotional legacy with her husband and children after her death which meant that she did not want to burden them with making decisions about her care, nor her concerns about her future. In addition, figure 14 (page 221) highlights that Deirdre also stopped socialising with her friends as the study progressed. As a result, Deirdre often shared her worries and distress about her deteriorating condition with me. Deirdre's concerns about upsetting her family were confirmed when, on two occasions, I called and we shared only short and perfunctory telephone call because Deirdre's husband was at home. In my field notes I noted,

> *Deirdre's husband was at home also which meant she was probably more guarded than she would have been had he been absent (Field notes from TC1 with Deirdre)*

Deirdre was quick to tell me that her husband was at home and was asleep on the sofa which I think was my signal that she wouldn't be talking about more personal issues on the phone today. She has mentioned previously that he doesn't cope particularly well with her illness so I certainly wasn't going to push her (Field notes from TC 5 with Deirdre)

Further to fulfilling the role of confidante, some participants began asking me to comment on their care – should they continue with treatment? Should they start this new treatment? What did I think? This became more prevalent as the study progressed and our relationship evolved. Although this could be viewed as a positive outcome of the flexible approach and telephone calls, for example a sign of trust; it presented me with a challenge. Ian asked me to explain what would happen to him when he went to clinic? What about his tumour count? These were questions that I was unfit to answer and thus I suggested that Ian talk with colorectal specialist nurses who were familiar with Ian's situation and supportive of his involvement in the study.

Similarly, I suggested that Deirdre chat with her GP with whom she had previously declared to have an excellent relationship, about her upcoming chemotherapy. At interview two Eve asked my thoughts on her recruitment into a clinical trial and later in the interview she reiterated that she had been referred to the hospice and asked me what 'palliative' meant. The quote below shows this conversation.

> "Eve   the nurses here at the clinic and at erm my surgery she said when they don't know, sometimes the Marie Curie nurses immediately pick up and say that's because of this and we can do this with it so fingers crossed. So palliative, I'm not really sure what palliative means. Do you?
> Emma   There are various things
> Eve   Right but I think I'm going to get the sort of grand tour" (Eve, 62 year old female, patient, time 2)

One of the advantages of the research ethics committee process is that I had previously considered where I would refer participants for advice and thus I felt well equipped to deal with the latter of the two situations above. Nevertheless the issue of blurred boundaries was exaggerated in the flexible interval group which could reflect the more evolved, and involved relationship I shared with the participants.

8.3 Part II Discussion

8.3.1 Overview of the findings

The findings suggest that it was the regular contact, as opposed to the flexible approach to the timing of the interviews that was responsible for enriching the already rich accounts. My relationship with the participants evolved in parallel with the monthly telephone calls so in some cases I was permitted earlier access to participants' private accounts of their experience. Moreover, the telephone calls informed the subsequent interviews and enabled me to capture processes and nuances that may have otherwise been neglected by the routine group when they were being described retrospectively. In addition, I determined what aspects of the experience might trigger an earlier than routine interview. Although earlier than routine interviews were carried out with only two of the eight participants, I learnt that the potential triggers were often potential losses to identity through the telephone calls.

So far in this chapter I have provided a reflexive account of how change was captured in this PhD study, by comparing and contrasting the six monthly approach to interviewing, with the flexible approach. Overall, the benefits and constraints that I have reported in this chapter were the result of the increased contact, rather than the flexible approach to the interviewing as I had originally hypothesised. In the section to follow I will discuss how a more nuanced type of change emerged as a result of the multi-faceted relationship and the contextual data that was generated from the monthly telephone calls. I will also consider when a flexible design, such as the one used in this study might be warranted.

8.3.1.1 Change or changing?

There is unanimous agreement that QLR is about change. It is the third facet of QLR, in addition to time and process which have broadly been the focus in the preceding two chapters. Indeed, Saldana (2003) simply puts it that QLR is about describing change using qualitative data. The regular contact with the participants in the flexible group contributed to a better understanding of why and how change happened, which is a key

aspect of contemporary QLR (Holland et al., 2006). In a number of cases I saw how small changes were precursors for bigger changes and thus, how the process of change evolved. This is in keeping with the iterative approach that QLR demands but moreover it supports Pettigrew's (1990) definition of QLR which describes the process of chang*ing* as opposed to change as a one off event (Pettigrew, 1990).

Lewis (2007) describes four types of change which I introduced in chapter three (Lewis, 2007). I would argue that the increased contact with the participants in the flexible group facilitated greater insight into each of these four categories.

1) The first type of change is narrative change and it reflects how the participants' stories change over time – the contextual information gained through the telephone calls provided a more detailed timeline of events over the course of the study. Moreover as my relationship with the participants intensified, they shared their private accounts on a more regular basis meaning I gained a more detailed picture of their thoughts and feelings about their situation. For example, Deirdre shared her fears about the emotional legacy she would leave with her children.

2) The second type of change occurs from the participants' reinterpretation and retelling of their stories – those in the flexible group were given more opportunity to retell and refine their stories. I heard about everyday experiences meaning I captured the small changes, which in some cases were catalysts or precursors for the bigger ones which happened at a later date. For example, I witnessed Deirdre's decision making process as she considered further treatment. One of the many advantages of QLR is that prospective and retrospective accounts of experience can be explored over time (Holland et al., 2006). This allowed participants to reflect, recount and recapitulate their experiences as the study progressed. However, the telephone calls also captured 'critical moments' as they happened which may otherwise have been forgotten or not prioritised in the subsequent interviews (Thomson et al., 2002). In this way participants were reminded of events or feelings that they may have otherwise thought insignificant,

giving them more context with which they could reinterpret and retell. This finding is supported by Taylor (2009) who also posited that the immediacy of some the transitions that the youths in her study experienced had been lost between waves of interviews. Whereas the increased contact through telephone calls or emails that she shared with her participants allowed her to witness change unfold in real time (Taylor, 2009).

3) The third type of change is evoked through the continuous reinterpretation by the researcher. As the study progressed I saw the participants differently in themselves and in relation to one another meaning, I was constantly reinterpreting their stories – this is the case during the data generation phase and the analysis phase. This reinterpretation was exaggerated as I developed a reciprocal relationship with the participants. As the findings above suggest, the data gathered from the telephone calls informed subsequent interviews in a literal way; a participant would tell me something on the phone and I would then probe further about it at the interview. But on another, subconscious level, the everyday chit chat about their lives influenced the data generation and the analysis in a very insidious way. Saldana (2003) suggested that researchers must confront their own preconceptions about change (Saldana, 2003). I have lost count of the number of times during this study that I have reflected on how quickly things can change – my notion of time was, and perhaps still is, being constantly revised after my experiences with the participants in this study. For example, Eve seemed reasonably well when we met for the first time and when I spoke on the phone a few months later she mentioned that she had been referred to the hospice. Likewise, I described in chapter seven (page 190) that I was shocked when Faye told me she only had a few weeks to live. On a practical level this meant I had a new and heightened awareness of the fragility of the participants' lives. I was more vigilant about keeping up to date with those in the flexible group and more concerned about contacting those in the six monthly group.

4) In some circumstances there was very little change – there was no critical moment as Thomson et al (2002) defined it (Thomson et al., 2002). In this study, no change was generally a positive thing for the participants. For example, Gordon played golf,

continued to go on holiday and was confident that he would receive good news when he attended the clinic. From those in the flexible group I learnt about potential threats to their identity but moreover I witnessed how the biographical work that was discussed in chapter seven was conducted. I was hearing about their everyday activities, which supports the idea that is with the normal everyday activities that participants find comfort and control (Shaha et al., 2003; Sjovall et al., 2011; Bury, 1982; Charmaz, 1983).

8.3.2 When is increased contact justified?

The findings in this chapter suggest that maintaining regular contact, with or without the flexible approach to interviewing, is recommended to counter three potentially problematic areas.

8.3.2.1 Countering attrition

As a result of the flexible approach I conducted two interviews that I would have otherwise have missed because Eve and Faye would have died. Unsurprisingly, attrition is exaggerated in QLR due to the longitudinal aspect; although in most cases this is probably due to losing contact with participants, rather than them passing away. Maintaining regular contact with the flexible group enabled me to counteract this problem – although as I alluded to earlier in this chapter it was not without its challenges. Although participants died in both groups, the telephone calls in the flexible group allowed me to find out about this in advance of the event rather than after. Two interviews sounds like a small number but in the context of this QL study it is not a small proportion. Had I been in regular contact with those in the six monthly group, I may have been able to interview Brenda, Duncan and Edward before they had passed away providing they had been willing and able.

No participants in this study withdrew which means I cannot say with any certainty that the telephone calls helped to keep participants recruited into the study. Nevertheless,

being able to get a sense of what was happening to them in real time meant I could keep up with the small changes that participants experienced – which in some cases were the precursors or the catalysts for the bigger changes. As the study progressed, the telephone calls were useful in keeping up with how people were doing and if they were going into hospital or hospice. Taylor (2009) describes a similar experience of researching vulnerable youths who led a transient lifestyle, and cites that the frequency of the contact she had with the vulnerable youth in her study improved retention (Taylor, 2009). Research which involves potentially transient groups of participants may also benefit from regular contact. For example, those suffering from mental health issues or addiction, or other groups who are regularly in and out of hospital like those with chronic illness or frail older people[30].

Other QL studies have described strategies to keep their participants engaged and their details up to date. For example the Inventing Adulthoods study used birthday and Christmas cards (Inventing Adulthoods, 2012). However this PhD study suggests that there are other benefits to interacting with participants on a regular basis which are similar to those of Taylor (2009). For example, sending cards does not provide contextual data whereas telephone calls or emails do.

However, there are few examples of the use of multiple methods in the QL health care literature. QL methods are still underutilised in health care research as the literature review in chapter three suggests. This could be explained by the relatively short length of the longitudinal studies. Andershed and Ternestedt (1999) supplemented face to face interviews with informal conversations with their participants in a QL study which explored relatives' experiences of caring (Andershed et al., 1998). Unfortunately they did not explore their reasons for doing so or if there was any added value. Goodacre

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[30] My colleague Anna Lloyd is conducting a PhD study to explore how the experiences of frail older people change over time. She too has incurred challenges when maintaining contact with her participants as they were often in and out of hospital.

(2006) used multiple methods to generate data for her QL study about women living with arthritis. In addition to face to face interviews and focus groups, Goodacre (2006) used diaries to gain perspective on the daily activities that the women conducted in their everyday lives. Goodacre (2006) argued that the diaries were beneficial in that it would have been difficult to elucidate that detailed information in the interviews but also, that the diaries informed subsequent interviews. Moreover the diaries helped Goodacre (2006) to follow the choices and decisions that the women made about managing their everyday activities (Goodacre, 2006). These latter two points support the findings in this chapter.

This PhD study has shown there is much to be gained from supplementing face to face interviews with telephone calls as a way of exploring change and for developing the research relationship. The use of other methods requires further exploration – the use of diaries might be useful for looking at everyday experiences and small changes but may be of little use for developing the research relationship. Future research could explore other methods of communicating with participants; particularly using technologies and social media. For example, Taylor (2009) described using email and indeed John asked if we could keep in touch via email (Taylor, 2009).

8.3.2.2 Exploring an unpredictable disease trajectory

The findings in this chapter suggest that a flexible approach, where regular contact is maintained throughout, is recommended when the topic under study is unpredictable. In the cases of Eve and Faye the trajectory of their illnesses took a downward turn – unpredictably from my point of view and from theirs. Due to the regular contact I was able to capture this time in their lives. Nissim et al (2009) incorporated flexibility into their research design to capture how the desire for a hastened death evolved over time for people dying of cancer. When the illness was stable, the serial interviews were conducted every two to four months but the intervals were shortened if the participant was hospitalised; began a new treatment regimen; if the self report measure that they

were using highlighted distress or if medical staff documented a significant decline in their physical condition (Nissim et al., 2009).

It could be argued that Nissim et al (2009) were maximising the opportunity to explore the changes that their participants experienced. In so doing they were able to capture the experiences of participants who might otherwise have died between the waves of data generation. Nissim et al's (2009) experience, and my own support Saldana's (2003) recommendation that a flexible approach is necessary in QLR because we do not know *what* change will occur (Saldana, 2003). I reiterate that neither do we know *when* change will occur which adds weight to the argument for a flexible approach.

8.3.2.3 Shifting control

Holt (2010) found one of the benefits of telephone interviewing to be that participants had control over the privacy of the call, and over their social space. Perhaps the relationship that I had with the participants in the flexible group resulted from those participants feeling more in control of their social space meaning that over time they felt more empowered than those in the six monthly group. Chapter six highlighted that participants in this study described experiencing a loss of control. Moreover, some described feeling powerless in that they had relinquished control to those looking after them.

This is consistent with the CRC literature in that loss of control is described in response to the diagnosis (Shaha et al., 2008; Worster et al., 2008). If the telephone calls enabled participants to feel more in control of their social space it may go some way to restoring their feelings of empowerment. Sturges and Hanrahan (2004) also commented that participants may be more comfortable discussing sensitive topics on the telephone and although they relate 'sensitive' to embarrassing, the same could apply to an emotionally sensitive topic, such as John finding out his prognosis (Sturges et al., 2004).

The purpose of the telephone calls was to look for change in the participants' circumstances with a view to conducting an interview which would capture change as it was happening. However, I had not expected the volume of contextual data that the telephone calls would produce to supplement the face to face narratives. One reason for this was that the telephone calls were chatty, friendly but most of all they were part of what people did in everyday life. This is in contrast to the research interview which, although I have argued in chapter four is in a sense an extension of a normal conversation, none of the participants had undertaken one before. For the most part, the telephone calls were not pre-planned, certainly not to the same extent as the face to face interviews, which meant I heard what was going on at exactly the time I phoned. For example, a participant would answer the phone saying 'oh I was just doing some gardening' or 'I've just come off the course' or 'my husband is asleep on the sofa'. Therefore, in addition to the telephone calls offering participants more control over their social space, they allowed a different side of the participants' experience to emerge which, as I alluded to earlier in this section, would have altered my interpretations and over time my reinterpretations.

8.4 Concluding remarks

Proponents of QLR advocate that a flexible approach should be used at all stages in the research process because we do not know what or when change will emerge (Holland et al., 2006; Saldana, 2003). In this chapter I explored how to best capture change using two approaches to generate data; a routine approach with six monthly waves of interviewing and a flexible approach. Although I only conducted two patient interviews, out of a possible twelve, earlier in the flexible group, there were clear benefits to maintaining regular contact with the participants. I gained rich contextual data to supplement the face to face interviews which informed subsequent interviews. I also developed a more evolved relationship than I did with those in the routine group. Pettigrew (1990) suggested change is a process rather than a one off event, and I would argue that the flexible approach that was used in this study allowed a more nuanced

understanding of the process of change to emerge. Given that there is unanimous agreement that QLR is about change this is an encouraging finding.

However, I was faced with some ethical dilemmas whilst using the flexible approach, despite the rigorous process associated with gaining ethical approval. Balancing the research agenda with the ethical agenda was a continuous process, and at every phone call and every interview it was necessary to ensure the wellbeing of the participants. I was personally challenged by some difficult phone calls, and I can only hope that I handled such situations in a sensitive and caring way. Although the same ethical challenges could have arisen in the routine interval group they did not, which suggests that some ethical issues are amplified when there is more intense contact. Moreover, what may seem like the optimum time to capture change in terms of the research agenda may not be the optimum time for the participant. The findings in this chapter suggest that intense contact with research participants is recommended when retention might be an issue, when the phenomena being studied is unpredictable, and when participants feel disempowered or lack control – these are all factors which may present themselves as challenges in health care research. Accordingly, further research on how to keep in touch with participants is warranted, particularly as we live in an increasingly technological world.

CHAPTER NINE

The issues revisited and implications for the future

9.1 Introduction

This thesis set out to explore the potential of QL interviewing for examining the experiences of those with metastatic CRC. In doing this, I have generated and analysed participants' accounts of their experiences of advanced illness, and how they changed over time. This concluding chapter comprises of three parts. Firstly, I directly respond to the three research questions that I posed in the introductory chapter of this thesis and highlight the ways that this study has developed the QL methodology. Secondly, I reflect on the strengths and limitations of this study. Thirdly, I consider the implications of this study and consider how the findings might inform future research, and further advance this methodology in the area of health care research. I conclude this chapter by reflecting on my own experiences and how I have developed as an independent researcher.

9.2 Part I - The Research Questions

9.2.1 Research question 1 - How can qualitative longitudinal interviews be best utilised to explore the illness experience?

"You've got my life story, thingwy will be round with that big red book" (Duncan, 57 year old male, time 1)

This study used a narrative approach to both interviewing and analysis. As the quote above from Duncan suggests, the narrative approach to interviewing, where I asked the participants to tell me what had happened to them, allowed them to start their story where they wanted, in their own time, and in their own words. In this way, the narrative approach to interviewing is a strength of this study because it is driven by the participants rather than the researcher. However, it is possible that participants only told

me what was important to them at the time or what they thought I should, or wanted to hear.

Several participants expressed their concern about my involvement in a study that was seen as emotionally demanding, and the effect it might have on me. For example, Brian suggested that I should not be doing 'this kind of work, at this age'. Perhaps Brian moderated his accounts in light of his concerns. Moreover, I likened my relationship with some of the women in the group to a mother/daughter relationship. They may also have moderated their accounts if they were worried that the content might upset me. However, I would argue that the combination of the QL design and the narrative methodology, allowed both the participants and myself to move beyond our preconceptions. As I described in chapter eight, the boundaries of my relationship with the participants seemed to blur as the study progressed. In parallel with this changing relationship, the nature of the accounts changed from public to private accounts. I was responsive to these changes within each individual interview which meant that sometimes I probed participants further and at other times I let the silences resolve independently of me. Akin to my experience, Cornwell (1984) described that the longitudinal aspect of her study granted her access to the participants' private accounts as the study progressed (Cornwell, 1984). Yet, as Saldana (2003) suggested, even within these private accounts there will be things which remain unsaid. Saldana's (2003) experience resonates with my own. Saldana (2003) reflected on his experiences of QLR having learnt that his participant of two and half years did not tell him about an earlier suicide attempt.

> "The experience with this study taught me that, despite how much is learned or disclosed to you over a long-term field work period, you will never know everything about your participants and must be careful about assuming you do. We all have deep, dark secrets that we want no one to know – even a trusted researcher who guarantees your anonymity and respects your confidentiality." (Saldana, 2003: 29)

9.2.1.1 The experience of metastatic CRC

To my knowledge there are no other QL studies to focus exclusively on the experiences of those with advanced CRC. I posit that the QL approach, and the narrative interviews

have enabled a nuanced understanding of the experience to emerge. Frank's (1995) typology of illness narratives (see section 2.7.2.1) neglects the experience of those who are terminally ill or dying (Frank, 1995). Thus, in chapter two I enquired as to what type of story the participants in this study might articulate. The narrative methodology of this study encouraged a narrative trajectory to develop which, over time reflected a beginning, middle and for some, an end. In chapter six I reported that the participants described a clear beginning which comprised of the diagnosis story. The middle was less well defined, and was characterised by uncertainty and reflected a liminal experience. Finally, for those who were able to tell it, the well-defined prognosis story represented the end of the narrative.

Participants described a gradual deterioration in their physical condition as the study progressed. In parallel, their physical appearance changed, which for many was a difficult transition because they felt, and looked well when we met at interview one. The physical deterioration affected the participants' ability, and desire to socialise which left some feeling isolated. Participants expressed a desire to maintain a semblance of normality in their lives, but in parallel with their deteriorating illness this became increasingly difficult. Taylor et al (2010) found that the participants with early stage CRC in were able to restore embodied control and return to a normal life (Taylor et al., 2010). In the literature review I questioned if this would be the case for those with advanced disease, are they able to return to a normal life? The findings in this study suggest that as the disease deteriorates, so too does the ill person's ability to engage with the social world in the way they want to, despite attempts to retain as a normal a life as possible. In this way illness potentially threatens identity for those who have metastatic CRC.

However, as the findings from chapter seven suggest, not all the participants experienced biographical disruption, although they all conducted some form of biographical work to restore or maintain identity, which is contrary to Bury's (1982) work. Biographical work was related to how participants saw themselves. For example,

in the earlier interviews, participants often used the 'you' voice to give themselves a collective identity. Latterly, they wanted to define an after death identity. Thus, I agree with Williams (2000) and Hubbard et al (2010) that biographical disruption should not be used as a standardised theoretical framework for describing the experience of illness (Bury, 1982; Williams, 2000; Hubbard et al., 2010).

Participants described the shock they experienced immediately after the diagnosis, and many asked the question why me? This was also seen in the literature, and in chapter two I questioned whether the participants in this PhD study would eventually accept the illness and stop asking why me. Interestingly, Chris and Faye both declared that they had accepted the fact that they would die, and indeed they both seemed at peace and able to tell a coherent and structured narrative. In chapter six I used the case of Ian to illustrate ticking clock. All the narratives in this study were told in the context of the ticking clock. Although accounts of uncertainty dominated the transcripts, not all of them suggested that the alarm had been set. However, Ian had been given a prognosis of two years, at which point he thought the alarm had been set. At the time of the third interview he was approaching the two year mark and as a result he was consumed by uncertainty and the thought he was approaching his death. In contrast, Faye and Chris had each been given a terminal prognosis yet their narratives seemed structured in comparison to Ian's chaotic story. This could suggest that if the uncertainty of *when* death will happen, becomes more of a certainty, the ill person's narrative resources are restored. This idea fits with the finding from chapter six that highlights the ill-defined nature of the cancer narrative from T2 when compared with the clearly defined prognosis story at T3.

Existential issues were most evident at T3, when participants were closer to the end of their lives. The notion of home and family took on new meaning, and the focus was on those who were being left behind. Participants learnt to cope with serious illness and part of doing this was to embed the cancer into their lives. They employed coping strategies to deal with the 'ups and downs', which they saw as characteristic of the

experience of cancer. At the first interviews, participants described having developed their own parameters of illness and wellness; weight loss was seen as bad and weight gain, the opposite. This did not appear as a theme at the time two interviews which could be explained that nearly all the participants had suffered deterioration in their condition by then. The positive rhetoric was heard through many of the interviews, but as the findings of this thesis suggest, this may reflect the public account of their illness experience.

Overall, the participants' accounts reflected being constrained in time and space. Pre-existing notions of temporality and a life plan were challenged by the diagnosis. For example, participants talked about biographical time – what their lives had been, what they had meant and how they were going to be remembered. In this way the participants' search for meaning in their lives changed over time. A question which was raised in chapter two in response to Lee and colleagues (2006), who found that the search for meaning can impact psychological and spiritual wellbeing (Lee et al., 2006).

Accounts of uncertainty were present in the transcripts at all time points, but latterly they co-existed with the certainty of death. This dual narrative highlighted an experience of CRC which is liminal, where the sufferer is living an ambiguous existence which is 'betwixt and between' (Hockey, 2002; Van Gennep, 1960). These findings are consistent with the few studies that explored the liminal experience of cancer (Little et al., 1998; Thompson, 2007). Interestingly, those who knew they were going to die imminently seemed to return to their 'master identity' where the home and the family were the focus.

This section has shown how the findings from chapter six and chapter seven interact to paint a detailed and complex picture. I consider the types of analysis in response to the third research question later in this chapter. But in short, the findings from chapters six and seven illustrate the strength and multi-dimensionality of QL analysis.

9.2.1.2 Coming back for more?

Had this been a cross-sectional study I would have gained a different understanding of the experience of metastatic CRC. For example, had I only interviewed the participants once, the accounts may have been overwhelmed by the diagnosis story, as Worster and Holmes (2008) experienced. The longitudinal design encouraged the participants to share their public, and latterly their private accounts of experience. For example, the findings which I presented in chapters six and seven required an understanding of how people embedded the experience of cancer into their lives. This study suggests that over time, within the certainty of death, identity may change.

Accounts of uncertainty were evident at all time points, which is consistent with the findings of Browne et al (2011) and Sjovall et al (2011). However, the impact of feeling uncertain, yet certain of death, was only understood later, as the private accounts emerged. Without this dual narrative I would not necessarily have identified the liminal experience, one of the key findings in this study. Likewise, the accounts of biographical work changed over time. If we had met only once, I would have understood how participants used the collective identity to define themselves, but not how they later entered a much more individual negotiation of the legacy they wanted to leave, and their after death identity. There were certain behaviours that were associated with belonging to a collective identity of cancer patients, such as being positive and stoical. Thus, had I met them only once I would have a limited understanding of how people coped with their illness at an individual level.

However, I cannot say with certainty that the findings I have presented would not have been produced had I conducted a cross-sectional study, because the QL aspect was written into the design. This meant the participants, and I knew that we would meet again. Indeed, Little et al (1998) conducted a cross-sectional study and found that patients with CRC enter a liminal phase at diagnosis in which they remain.

Overall, I would argue that being able to follow participants as they approached the end of their lives offers a nuanced understanding of experience, that is sufficiently convincing to argue for a QL design being worthwhile. Moreover, it is interesting to note that when participants were asked to share their stories in their own words, the themes which arose over time highlight issues of identity. This is contrary to what I expected, insofar as although present, I thought themes of service provision, unmet need, communication, and relationships with health care professionals would dominate the accounts. This could suggest that what we, as health care researchers think is important to participants, may not be a priority to them.

9.2.2 Research question 2 - What is the added value of a flexible approach with regard to the frequency and timing of longitudinal interviews?

During the design of this study there were a number of discussions about when the waves of interviews should be carried out. Initially it was thought that an interval of four months seemed appropriate, but it became apparent that this might be too frequent, given that many of the potential participants I met at the clinic described themselves as reasonably well. I shared my concerns with the staff at the recruiting centre who agreed, and as a result, the interviews were scheduled at six monthly intervals. The intervals between waves of data generation in QL studies are often based on empirical evidence, but are mainly driven by the aims and objectives of the research (Corden et al., 2007a). However, as the literature review demonstrated, there are no other QL studies which concentrate solely on the experiences of those with advanced CRC; meaning the best approach, was to consult the experts at the recruiting centre for their advice. Overall, I felt that the six monthly intervals between the waves of data generation seemed to work well. The participants remembered who I was, and remembered about the study. I sometimes had to remind them what was happening at the time of the previous interview, but I would argue that this was useful, as it gave me the opportunity to show that I had been listening to them which encouraged a trusting relationship.

To move beyond exploring the potential, in order to develop the QL methodology for health care research, this study was also designed to examine the added value of a flexible approach to the timing of the interviews. With a view to conducting an interview as close to when a change occurred as possible, participants in the flexible group were telephoned on a monthly basis, so I could keep up to date with changes in their circumstances. In chapter eight I compared and contrasted the six monthly, routine approach and the flexible approach. The telephone calls triggered two early interviews, with Faye and with Eve, which supports my argument that the six monthly interval between the interviews was appropriate. However, the increased contact that resulted from the telephone calls allowed me to build a better picture of the participants' experiences due to the context they provided. This context also meant that I had more detail to inform subsequent interviews. The increased contact led to a more evolved and involved relationship with the participants in the flexible group, and a more nuanced understanding of the experience emerged. The relationship, and the nuanced understanding are not mutually exclusive and it is impossible to say whether the relationship facilitated a greater understanding of experience, or the greater understanding led to a more involved relationship.

Were the phone calls worth doing? I felt more prepared for the subsequent interviews with the participants in the flexible group due to both the relationship and the context providing stimulus for the interview. However, the ethical issues which I detailed in chapter eight did not occur in the routine group. The telephone calls added to the already time consuming nature of QLR, as it often took several attempts to make contact with participants. In addition, there was the added analytical burden of how to use the data that were generated through the telephone calls, albeit they were field notes as opposed to transcripts. The findings in chapter eight also suggest that intensive contact with participants is justified if retention might be an issue, when the phenomena under study is unpredictable and when participants feel disempowered or that they lack control – I would advocate for regular contact with participants as these represent potential issues for health care research.

The findings in chapter eight prompted me to consider whether the same outcome might be achieved using other methods of communication, such as email, blogging and texting. These, may be good for providing context, but I believe that the telephone calls fostered our relationship. The participants were used to speaking on the phone, as was I, but more than that; there was something distinct about catching the participants as they were living their normal lives. I believe that this prompted some intense and meaningful conversations. I would like to investigate this in future research, particularly in the context of end of life research, when participants become physically weaker over time. Overall, the flexible approach enriched already context-rich accounts of experience.

9.2.3 Research question 3 - Which approaches to analysis are most valuable for qualitative longitudinal interviews?

This study set out to explore the multi-dimensional nature of QL analysis. QLR is known for the analytical opportunities it presents in terms of direction, as I described in chapter three (see 3.3.3). For example there is i) Cross-sectional analysis at each time point, ii) Across time analysis, across cases, iii) Across time analysis, within cases (Holland et al., 2006; Holland et al., 2006). QLR is also known to produce a large volume of data, and this study is no exception. The volume of data that was produced required me to be organised and methodical when conducting the extremely time consuming analysis. The seemingly straightforward account of conducting the longitudinal analysis that I provided in chapter four, is not able to capture all the complexities of the reality. Moreover, the iterative approach and constant reinterpretation that QL analysis demands, added to the complexity, albeit this is also its strength.

The findings from chapters six showed how the analysis can be conducted cross-sectionally (Part I) at each time point and through time analysis, across cases (Part II). The findings in chapter seven show how the analysis can be conducted through time, within cases (Holland et al., 2006). Together these chapters showcase the variety of

directions that can be adopted in QL analysis, but also enable a detailed understanding of experience. However, little is known about the best type of analysis to use in QLR. Accordingly, this study adopted two types of analysis; namely narrative analysis using the VCRM (Brown et al., 1992) and thematic analysis based on the principles of grounded theory (Charmaz, 2006). These were discussed in detail in chapter four (4.8).

As the literature review in chapter two illustrated, there is a growing body of support for narrative research methods, and I would argue they are particularly relevant in QLR where a story is being told over time. One of the major advantages of narrative analysis, and the VCRM in particular is that there is little, or no fragmentation of the stories that participants tell. Unfortunately, I found no previous reports on how to conduct the VCRM longitudinally[31] thus was working blindly. Given this gap in the literature I hope this thesis will contribute to the limited body of knowledge that currently exists.

The VCRM analysis was well suited to the data that were generated from the narrative interviews, as participants told long stories, with little interruption[32]. As its name suggests it is both voice-centred and relational, thus it has the participants' voices at its focal point (Brown et al., 1992). This is a particular strength of the VCRM, but in addition to this, I gained greater understanding of the accounts by studying the form of the participants' narratives. For example, it was through reading one, for the overall plot of the story that I became aware of commonalities in the types of stories that the participants told; diagnosis story, cancer story and for some, prognosis story. In contrast, the content of the stories; the signs and symptoms; the first appointment with the doctor; the diagnostic tests; the operation; the chemotherapy, was more likely to be identified through the thematic analysis.

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[31] Although Brown and Gilligan's (1992) study in Meeting at the Crossroads is longitudinal they do not describe how they used the VCRM across time (Brown et al., 1992).

[32] The transcript for my second interview with Duncan has 5 single-lined pages of his narrative with only minor utterances from me.

The VCRM also highlighted sub-narratives; in other words stories within stories. I introduced the idea of sub-narratives in the case histories of Faye and Duncan in chapter seven. The sub-narratives served several purposes. In the first interviews, some participants told stories about the deaths of friends or family as a way of introducing death in an indirect and non-threatening way. Through these sub-narratives about others, participants also expressed their fears of how their illness might progress. However, over time participants seemed more likely to use the sub-narratives to biographically locate, and embed their own experiences of cancer. Following the sub-narratives over time highlighted the key themes around identity, which were revisited earlier in this chapter.

In chapter seven, I also reflected on the use of the 'you' voice and how the participants identified themselves as part of a collective. This finding originated directly from reading two of the VCRM, which is how the participants speak about themselves. Although I cannot say definitively, I think it unlikely that I would have identified this using the thematic analysis alone. Since using the VCRM for the purpose of analysis, I have noticed how often people use 'you' when they could use 'I' in everyday conversation, myself included. It is for this reason, that without this particular focus on how the participants used pronouns in the VCRM, I believe it would have gone unnoticed.

Despite the strengths of the VCRM, as I got to know the participants better over the course of the study it became increasingly difficult to see the commonalities between them. In this way, the thematic analysis was particularly useful. The findings that I presented in chapter six, which described the experiences of the group across time, were mostly the result of the thematic analysis. However, unlike the narrative analysis which values the stories as the participants narrated them, the thematic analysis demands that the researcher code the transcripts and in so doing fragment the story into meaningful extracts (Charmaz, 2006). I found this challenging having already conducted the narrative analysis prior to the thematic analyses. It is for this reason that it would have

been unfeasible to compare the narrative and thematic analyses. Both were conducted concurrently, by me, meaning each was informed by the other and they were in conversation with each other from the outset (with the exception of the narrative analysis from time one which was the first analysis).

Overall, the analysis that I conducted in this study was extremely time consuming. Holland et al (2006) comment that QLR triples the analytical burden that already exists in qualitative research, and by conducting two types of analysis I effectively doubled this again (Holland et al., 2006). Moreover, the longitudinal and iterative nature of the design means that the analysis is a constant reinterpretation of the findings; within each transcript, between each participant and from one time point to the next. Having said this, I would not have the same detailed understanding of the accounts of the participants' experiences had I done things differently. Holland et al (2006) suggested that the complex datasets that result from longitudinal data collection 'demand innovative strategies for data analysis and display' (Holland et al., 2006: 38). I propose that using the VCRM over time, and analysing and presenting the findings using the timelines in chapter seven was innovative, particularly in the area of health care research.

Graphical devices have been used in QLR as 'elicitation stimuli' to hear life stories, a process which Crilly (2006) described as graphic ideation (Crilly, Blackwell, & Clarkson, 2006). For example, Hanna and Lau-Clayton (2012) described how they used timelines to facilitate conversation and to help the young fathers in their QL study to structure their biographies (Hanna & Lau-Clayton, 2012). Similarly, Thomson (2004) used lifelines, in addition to interviews, memory books and focus groups, with young people (Thomson et al., 2004). However, the use of visual methodologies for the purpose of QL analysis is sparse. It is noteworthy that it did not arise in the literature review in chapter three. Visual representations, such as the timelines used in chapter seven have the potential for summarising the key themes and how they changed over time. In my experience, the timelines encouraged time and change to be the focal point

of the analysis, which is the essence of QLR. Moreover they may be a familiar mode of communicating to those working in health care, who are used to seeing figures and tables in academic publications. It is for these reasons that I believe the use of diagrammatic timelines for the purpose of analysis and presentation in this PhD is innovative, and has moved the methodology forward.

Given the wealth of analytical opportunities for those using the QL approach, we as researchers have a responsibility to manage and present the data in ways that advance the methodology. I have contributed to doing this by developing a structured way of analysing QL and multi-perspective data over time, which is sensitive to health care research.

9.3 Part II - Strengths and limitations

In response to the research questions I have addressed some of the strengths and limitations of the study. In the section to follow I highlight some of the more general, yet pertinent limitations.

9.3.1 Missing voices

This study reflects the accounts of 16 participants with metastatic CRC, and eight of their carers. They were recruited from the same centre within a period of nine months. Different accounts would have been heard had I recruited different participants at a different time, and from a different place. The group were homogenous in terms of ethnic diversity hence ethnic minority groups are under-represented. Likewise, those with a permanent stoma were also under-represented and the literature suggests that there might be experiences which are specific to them. Moreover, those with moderate to severe memory impairment and those who were considered to be approaching the terminal phase were excluded from the study. The clinical findings from this study are not immediately generalisable to all those with advanced CRC, nor were they intended to be. Rather this study was designed to afford a rich and contextualised account of the

experiences of a group of participants with advanced CRC (Polit & Beck, 2010). However, the QL approach meant that I was able to follow participants as they became sicker, so those with severe illness were represented, which is a strength. No participants withdrew from the study which suggests that the method of recruitment and the QL approach were acceptable to participants in an area which is known to be difficult to conduct research.

Overall, the process recruitment was both successful and enjoyable, but it took longer than either I, or the health professionals at the recruiting centre had anticipated. The main reason for this was that the pool of potential participants became smaller each week. The consultants were reluctant for me to recruit participants who were very newly diagnosed meaning there was a delay of several weeks and sometimes months for every newly diagnosed patient. One potential limitation of recruiting participants from the clinic at the recruiting centre was that they may have perceived me in a certain way - as a nurse, and what I wanted them to talk about - their experience of care. If narratives are told for a particular audience then how they perceived me as their audience is important (Elliott, 2005). I have reflected on my position throughout this thesis because I believe that the research relationship was integral to how change was captured in this study. By reflecting on my own position in the research and how I may have influenced participants' accounts, whether consciously or subconsciously, I have attended to the co-constructionist epistemology upon which this study is based.

9.3.2 The multi-perspective approach

This study adopted a multi-perspective approach, where I interviewed the participants' informal carers if they nominated one, and the carer was willing. In a paper which I co-authored during this PhD study we reflected on the potential of multi-perspective interviewing for providing a comprehensive account of the participants' experiences (Kendall et al., 2009) (See appendix two, page 292). Likewise Taylor and de Vocht (2011) recently reflected that a multi-perspective approach can add to the richness of the

data (Taylor & de Vocht, 2011). Thus, the aim of the multi-perspective approach was to further contextualise the participants' accounts. In this way the bereavement interviews were particularly useful, as I was given access to stories about each participant's death. The bereavement interviews were the only way to gain information about the final days of those who died, and the established relationship granted the carer and myself closure.

When a carer was present and willing to participate I gave the participant and the carer the opportunity to be interviewed together or separately. Only one patient/carer dyad chose to be interviewed individually which is consistent with Morris's (2011) experience (Morris, 2001). Morris (2001) found that the discussion of sensitive issues between the dyads was common, and sometimes it was the first time that they had discussed their experiences. This is both a strength and a limitation, in that it could be a therapeutic benefit of the multi-perspective approach, or a potentially harmful outcome. I described my experience with Gordon and his wife Kate in chapter six. They reflected at the subsequent interview that it was the first time they had spoken about how Gordon was preparing for his death, but for them this was a positive outcome. Nonetheless, I acknowledge that this could also have negative implications for those involved, and throughout the study I paid careful attention to the emotional wellbeing of the participants.

9.3.2.1 Reflections on the bereavement interviews

The uptake of the bereavement interviews with carers was variable. Chapter five described the chronology of the interviewing and more specifically section 5.3.3.1 (page 112) described how two carers declined to participate in bereavement interviews at T2. Figure five (page 114) illustrated that three bereavement interviews were conducted at T3. One reason for this could be that the carers who were bereaved at T3 felt more invested in the study when compared with those who were bereaved at T2. There were several benefits to conducting the bereavement interviews. Firstly, they added the final chapter to contextualise the participant's overall story. It is in this way that the data from the bereavement interviews added yet another layer of complexity to the analysis and

interpretation of the overall narrative (for an example of this see 8.2.1.2, page 223). Secondly, the bereavement interviews also afforded the carers the space to de-brief and reflect on the death of their loved one.

9.3.3 Researching a sensitive topic

It is thought that ethical issues are exaggerated in QLR (Murray et al., 2009; Holland et al., 2006). This is consistent with my experience in this study, insofar as more contact with the participants led to more ethical challenges. This study highlighted the challenge of balancing the ethical imperative with the research imperative. Chapter eight detailed some of the more difficult situations I experienced (page 232) and I conclude that what may seem like the optimum time to interview in terms of the research agenda, may not be the best for the participant. The participants felt invested in this study, just as I did, therefore they did not want to feel that they were letting me down by not participating. Although their commitment to the study was very much appreciated I did not want their participation to have a detrimental effect on their emotional and spiritual wellbeing. Situations like this highlight the complex nature of conducting health care research with those who are seriously ill. The findings from this study suggest that there has to be flexibility in terms of the research agenda, and tact and sensitivity on the part of the researcher.

Having said this, I also believe that in giving the participants the opportunity to share their story with someone who was out with their family, and out with their medical team was, for the most part, therapeutic. This finds support in Taylor's (2009) QL study with vulnerable youths (Taylor, 2009) and I think this quote from my final interview with Andrew and his sister Gill, gives weight to my argument.

"Andrew   I think talking about it helps.
Emma   Do you?
Gill I think talking about it helps as well
Emma   Good. I'm pleased to hear that
Gill   Because I think when Andrew is talking to an outsider *(yeah)* it's something that he probably needs, because he wouldn't say a lot *(yeah)* that he's said to…
Andrew   I probably wouldn't… to be honest, I probably wouldn't… Gill's right, I probably wouldn't say as much *(yeah)* to my sisters *(yeah)* than I would to someone else *(yeah)*, if you know

what I mean. Because, as I said, I do keep a lot of things *(yeah)* to myself." (Andrew, 59 year old male, patient and Gill, female, sister and carer, time 3)

The therapeutic potential of qualitative interviews remains a contentious issue and thus I broach it tentatively. However my reflections do find support in the literature (Peel, Parry, Douglas, & Lawton, 2006; Lowes & Paul, 2006; McGrath, 2003; Murray et al., 2009; Dickson-Swift et al., 2006; Taylor, 2009; Holland et al., 2006). Moreover the longitudinal aspect allowed participants to reflect on their own stories. Perhaps in doing this they were able make sense of their illness, as the quote from Frank (1995) that I presented at the very beginning of chapter two suggests (Frank, 1995).

9.4 Part III - Implications and recommendations

This thesis was designed to explore the potential of QL interviewing for examining the experiences of those with metastatic CRC and their carers. In this chapter I have directly responded to the research questions I posed in the introduction. In doing this, I have showcased the benefits of using a QL approach and highlighted the challenges but have also shown that this study has developed the QL methodology in terms of data generation and analysis. The QL design of this study produced a nuanced and contextualised understanding of how the participants' accounts changed over time which reflected the dynamic experience of advanced illness. Furthermore, I fostered a trusting relationship with the participants which afforded them space to share their public and private accounts of experience. Overall, this thesis suggests that QL interviewing offers a way of understanding the experiences of those with metastatic cancer which appreciates notions of temporality, process and change. In this final section, I consider the implications of this study in terms of future research.

This study contributes to the limited body of knowledge that currently exists regarding the application of QL methods for health care research, particularly in the areas of end of life and cancer care. In this thesis I have demonstrated the potential of QLR, but have also advanced the methodology through the interplay of the findings and the methods.

However, for the potential to be fully realised, a methodological dialogue is required which is tailored to the issues incurred by health care researchers. My hope for this thesis, is that together with the papers that I co-authored, (appendices one and two) I can encourage such a dialogue to develop.

Much has been learnt from the methodological reflections of social scientists, as this thesis demonstrates. I acknowledge and appreciate the importance of multi-disciplinary scholarship but I also believe that in order to advance the use of the QL methods for health care research, there needs to be an appreciation of the issues which are specific to the research area. For example, issues relating to recruitment and negotiating with gatekeepers who may be reluctant to involve patients in what they perceive to be a potentially onerous study. This may be particularly true of studies which relate to the end of life, or involve potentially 'vulnerable' groups of participants. Participants may get progressively more ill as the QL study progresses, meaning different methods of generating data may be more appropriate. Holland et al (2006) reported that flexibility should be inherent in the QL design (Holland et al., 2006). Health care researchers need to find a way of making the most of this flexibility, within the boundaries set out by the ethics committee.

- I believe we need to develop a canon of methodological literature that is specifically tailored to reflect these potentially complex issues. I appreciate that there is a limit to what researchers who are currently using QL methods can report in publications that have a short word limit. However, this means we have to publish more methodologically orientated papers which permit the space for transparent and reflective accounts of using the QL approach. It is in this way that we can advance this emerging research paradigm and use it to its full potential in health care research.

- According to Holland et al (2006) QLR should use innovative approaches (Holland et al., 2006; Saldana, 2003). Thus new and contemporary strategies for generating

data are warranted. One of the participants in this study asked if he and I could communicate via email instead of telephone calls. Although it was out with the scope of this study (and out-with the scope of my ethics approval), this prompted me to think about other methods of communicating with participants. For example, diaries, emails, text messages, photographs, art. I propose a pilot research study to ask those with advanced and/or chronic illness, who are at different stages on the illness trajectory how they would prefer to communicate in a research project. This pilot study could be used to inform an exploratory study to compare and contrast various methods of generating data in a QL study, for people who are approaching the end of their lives. This study would encourage the use of research methods which are participant-led – not only would we hear the voices of those who are often silenced, but we would hear them in the way that participants themselves want them to be heard.

- The use of timelines for analysis and presentation was innovative and further future work could explore using timelines as a tool to feed back the results to participants after each wave of data generation. This would encourage 'graphic communication' as Crilly (2006) described it, but would also promote research which is both participatory and rigorous (Crilly, 2006).

- This study has highlighted the advantages of using a narrative approach to analysis over thematic techniques. However, as I was conducting both concurrently I am unable to offer a comparison. Given this, future research could employ the analytical skills of two researchers to offer a more definitive comparison. There will always be challenges in doing this because the researcher who conducts the interviews will have already started analysing the data at that time. Nevertheless, I believe it would be a worthwhile question to pose, given that thematic approaches tend to dominate the qualitative health care literature.

- In this study the participants' accounts reflected a clear beginning, middle and for some, an end. How does this compare to those who are suffering from other illness, or those who are frail and are approaching the end of life? Together with my colleagues from the Primary Palliative Care Research Group we in the preliminary stages of writing a paper, using our in house studies, to compare these different narrative trajectories.

As the literature review in chapter three demonstrated, the current literature on the experiences of CRC is heavily weighted to survivorship studies. To my knowledge this PhD study is the only QL study to focus solely on the experience of those with metastatic colorectal cancer. Thus, it redresses the balance insofar as the QL approach led to a nuanced and rich understanding of how the participants in this study described living with, and dying of metastatic CRC. However, I attend to the implications cautiously. This study set out to explore the QL methodology in the context of the experience of metastatic CRC. Had the aim of this study been primarily to explore the experiences, I may have approached the interviews and analysis differently. Having said this, I acknowledge my responsibility to interpret and disseminate the findings.

- The experience of advanced CRC is a liminal one, where uncertainty about how the illness will progress, co-exists with the certainty that death is approaching. Douglas (1985) described the person who is in a liminal phase as vulnerable (Douglas, 1985). With a view to improving the experience of dying, further research should explore the liminal experience in the last few weeks and days of life. Moreover, the notion of home took on new meaning at the end of life, hence further research should explore the liminal experience at home and in the hospice, which is classed as a liminal place where people hover between life and death.

- The findings from this study suggest that when death was imminent participants seemed to return to a master identity where family was the focus. With a view to

improving the experience of dying, future research should explore the sense of identity, and family in the last few weeks and days of life.

- Participants conducted biographical work to manage and maintain their sense of self. One way they did this was to reflect on their legacy and negotiate how they were going to be remembered after their deaths. For some, this was practical and involved leaving financial security, but for others it was emotional. Further research should explore the benefits of an early intervention to support people with CRC to plan for the future and secure their after death identity (Exley, 1999).

- The voices of those with a permanent stoma were under-represented in this study and the literature suggests that there are experiences which are specific to this group. Therefore, I suggest a further study to specifically explore their experiences, and those of their carers as they approach the end of their lives.

- Likewise the accounts of those from ethnic minority groups, with different religious backgrounds and post mortem practices were missing from this study. Thus, I suggest further research in this area, as they may experience liminality and identity change differently.

9.5 At the end

As I described in chapter one, this thesis marks the culmination of my journey to becoming an independent researcher. I have developed the necessary skills of research practice, but more than that, I have gained much by being embedded in a department which is passionate about improving the experiences of those who are approaching the end of their lives. Listening to the stories that the participants shared with me throughout this journey has challenged me and changed me. My supervisor recently asked me to reflect on the suitability of this study for a PhD student. Was it too emotionally demanding? Was it appropriate for someone of my age? Was Brian right

that I should not be doing this kind of work? I think my nursing background was beneficial as I had cared for people who were dying and their families and in this way I felt somewhat prepared. When I respond to being asked what my PhD is about, there is generally concern about how I deal with such an emotionally demanding subject. One of the benefits of being a PhD student is that I have been able to de-brief during my formal supervision meetings and informally to my colleagues. Although at times it was upsetting, and of course I was always sad to hear that the participants had died, I continue to be inspired by those who gave up their precious time to be interviewed for this study.

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APPENDICES

APPENDIX 1. Co-authored, published journal article one

This is the first of two articles which I co-authored with my colleagues from the Primary Palliative Care Research Group at The University of Edinburgh,

Murray, S. A., Kendall, M., Carduff, E., Worth, A., Harris, F. M., Lloyd, A., Cavers, D., Grant, L., & Sheikh, A. 2009, "Use of serial qualitative interviews to understand patients' evolving experiences and needs", British Medical Journal, vol. 339, 958-960.

URL to QL paper: http://www.bmj.com/cgi/content/full/339/sep28_1/b3702

RESEARCH METHODS & REPORTING

Use of serial qualitative interviews to understand patients' evolving experiences and needs

Scott A Murray, Marilyn Kendall, Emma Carduff, Allison Worth, Fiona M Harris, Anna Lloyd, Debbie Cavers, Liz Grant, Aziz Sheikh

Interviewing patients over the course of their illness can give a much better picture of their experience than single interviews, but the approach is rarely used. **Scott Murray and colleagues** explain how to get the most from it

Primary Palliative Care Research Group, Centre for Population Health Sciences: General Practice Section, University of Edinburgh, Edinburgh EH8 9DX

Correspondence to: S A Murray
scott.murray@ed.ac.uk

Accepted: 26 March 2009

Longitudinal qualitative research offers considerable advantages over the more typical single "snapshot" techniques in understanding patients' changing experience of illness. Serial qualitative interviews are a convenient and efficient approach to developing an ongoing relationship between the participant and researcher, thereby facilitating discussion of sensitive and personal issues while also allowing exploration of changing needs and experiences.

Serial interview studies are widely used by social science researchers in anthropology, criminology, education, psychology, and social policy.[1-6] However, they remain underused in medicine.[7] Using our experience with the technique, we suggest when researchers might wish to use serial interviews and discuss the methods, the data generated, and how to avoid potential pitfalls.

When to use serial interviews

Serial interviews are suitable for research that aims to explore evolving and complex processes or when time is needed to develop a relationship between researcher and participants. We have used the approach to study the changing experiences and needs of people with lung and brain cancers, heart failure, severe chronic obstructive pulmonary disease, and spiritual distress, and access to care for south Asian patients at end of life (table, see bmj.com).[8-11] Others have shown the value of this approach in, for example, understanding childhood asthma, exploring stigma related to HIV infection, reconstruction of self identity after diagnosis of chronic fatigue syndrome, complex clinician-patient interactions around requests for physician assisted suicide, and the symptom course in childhood cancer.[12-16]

Serial interviews can also be used to identify changes in what patients want, the most acceptable way to carry out interventions, and which outcomes are most important to patients at what times. Allowing the participant-researcher relationship to develop over time enables the generation of more private accounts and descriptions of sensitive topics that are less accessible in initial interviews. Serial interview studies can also be embedded within complex intervention studies in order to try to elucidate causal pathways. For example, we are including serial interviews in our trial of using lay outreach workers for smoking cessation in order to understand why they are (or are not) effective.

How do you conduct serial interview studies?

Recruitment

The timing of initial recruitment is important and is best driven by a sound understanding of the likely trajectory of the illness and the main issues to be explored.[17] For example, we recruited patients with lung cancer at the point of diagnosis; those with heart failure at the time of their admission to hospital—when supportive and palliative care needs become particularly relevant; and patients with glioma before formal diagnosis in order to capture their experiences from this distressing time onwards. However, when prognostic uncertainty is great, the timing of recruitment for initial and subsequent interviews can be difficult to determine.

Location of recruitment also needs consideration. Identification in hospital can be successful for patients with rare conditions, who can then be followed up in the community. However, different situations may require recruitment in other healthcare settings or even outside health care. Irrespective of where participants are recruited from, working closely with all professionals involved is crucial to ensure appropriate and ongoing access to participants. In order to make the best use of resources inclusion and exclusion criteria must be well defined, including the stage of the illness.

Data generation

Variable attrition rates and illness progression will affect the timing of second and subsequent interviews. For example, we used three month intervals in people with recently diagnosed lung cancer but six monthly inter-

SUMMARY POINTS

Serial interviewing studies can give important insights into patients' changing experiences of illness

The increased contact with participants allows a deeper relationship to develop, facilitating discussion of sensitive issues

Theoretical and methodological concerns can be overcome with careful planning

Although the method is time consuming, the benefits are well worth achieving

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views in people with chronic obstructive pulmonary disease, which progresses less rapidly. Researchers should identify expected transitions or key points in the course of an illness and return to speak with participants at those stages. We have also found it useful to use telephone contact to assess if an interview should be brought forward to capture a changing event. The time needed for repeat interviews must be factored into the research design timetable.

Data generation must continue long enough to describe and understand the trajectory being studied. In patients with lung cancer, for example, data collection for 12 months from diagnosis will capture most deaths, but longer will be needed in a study of frail elderly patients.

Analysis

Initial analysis of transcripts of individual interviews and field notes should take place immediately, alongside continuing data generation. This allows emerging themes and concepts to be further tested and developed in subsequent interviews. Analysis may also be done across all first, second, and subsequent interviews or data synthesised from interviews at specific key points, such as immediately preceding death.

Adequate time and resources need to be allocated to allow the various longitudinal analytical opportunities to be fully exploited. Analysing all transcripts for each person as a longitudinal single unit will provide a sense of individual experience, whereas broad thematic approaches build cross-cutting themes, but at the expense of individual contexts. The longitudinal datasets generated, being typically rich in narratives, allow innovative approaches to both transcribing and analysis. For instance, as the required coding in qualitative analysis can result in fragmentation and decontextualisation, we have transcribed some parts of the interviews of heart failure and lung cancer patients in stanza forms, as epic poetry. These can provide an accessible insight into the patient's experience.

What type of findings might you expect?
Issues that change over time

Serial interviews can elicit changing needs or opinions—for example, in our lung cancer study some participants went from initial enthusiasm about having chemotherapy to regret, and others from refusal to deep appreciation of hospice care in later interviews. We were also able to capture the fluctuating existential anguish of increasing physical and cognitive debility in serial interviews with glioma patients and their carers. Similarly, Baker and colleagues interviewed bone marrow transplant recipients and noted changing physical problems and anxiety levels as the treatment progressed, with a feeling of impending doom emerging in later interviews.[18] The serial interviews provided a rich insight into the multifaceted roles of patients within their families and communities and the way in which these served to preserve patients' identity over time.

Serial interviews can also show how patients' experiences can be affected by external factors such as the influence of health services on their conceptualisation of illness over time.[19 20] Furthermore, serial interviews allow fluctuating and often asynchronous patterns of physical, social, psychological, and spiritual distress to be discerned. The approach allowed us to map typical trajectories of physical decline in people with cancer and organ failure.[21] We were also able to identify typical but asynchronous trajectories of psychological, social, and spiritual distress as disease progressed in patients with advanced lung cancer.[21 22] We were able to describe archetypal typologies of decline by following individual cases over time. This gave a much clearer picture than would have been possible by simply comparing snapshot data at different stages in the disease.

Rich and contextualised accounts

Repeating interviews allows narratives to unfold, revealing the complexity of individual situations, and helps participants and researchers to highlight deficiencies of care and make suggestions to improve services. Experiences since the last interview can be shared, with the earlier findings being developed and reflected on in the context of an evolving, participant-researcher relationship. The resulting continuous and changing account would be difficult, if not impossible, to construct from a series of snapshot interviews. Additionally, the trust fostered by repeated contact enables participants to voice sensitive or embarrassing issues and allows more private (as opposed to public) accounts to emerge.[23] We have found that repeated interviews give participants implicit permission to broach what was previously unspeakable, facilitating frank and honest discussions that might otherwise not have occurred. Detailed and contextualised accounts of sensitive illness experiences can therefore emerge.

Pitfalls and how to avoid them
Ethical issues

Ethical problems are potentially heightened in longitudinal research, including concerns around serial consent, especially if the patient is deteriorating or vulnerable.[19 24] Intrusion, dependency, and distortion of life experience must also be avoided.[25] But we have found that patients can, and indeed want to, talk about personal and sensitive issues such as death, dying, and bereavement. Patients have said that it is sometimes easier for them to talk to a researcher rather than a clinician about these issues, and that by voicing their internal fears they have been more able afterwards to speak to their family members and friends. Serial interviews also give participants the opportunity to voice their concerns and distress and make a societal contribution through research in response to the care they have received.[26 27]

Serial interview research can place considerable demands on researchers because it is inherently an emotionally charged process. Researchers' responsibility does not end with a final interview, and it is important to protect the wellbeing of researchers as well as participants. Accordingly, we recommend counselling and debriefing sessions for both researchers and transcribers, who should ideally have adequate maturity, experience, and access to personal or emotional support.[28] Our experi-

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ences confirm that these concerns about wellbeing can be adequately addressed and that interviewing very ill patients need not be exceptionally stressful.[28]

Attrition

As with any longitudinal research, attrition can be problematic. For example, in one study of people with glioma, none of the planned second interviews were possible because of participants' cognitive decline and lack of energy after radiotherapy.[29] Steinhauser and colleagues emphasise the importance of establishing participant-interviewer rapport from the first point of contact to try maximise retention.[30] If a firm relationship is built up between researcher and participant, few participants will be lost, except through debility or death. Nonetheless, attrition should be factored into the design of the study. We found that by recruiting and interviewing patients and their relatives early in their illness we were able to establish relationships that facilitated interviews with relatives after patients' deaths. Grieving relatives often felt more able to take part in a bereavement interview with someone they knew and trusted, and who knew and understood their journey.

Data overload

The serial interview approach inevitably generates a large volume of interviews. The data can become difficult to manage, particularly when second and subsequent interviews have started. Effective planning is therefore essential from the outset. Furthermore, the time consuming nature of the analysis creates the danger that the process is becoming unmanageable—something that has been described as an analytical albatross.[31]

Conclusions

An understanding of the dynamic effects of disease on people's everyday lives is a prerequisite to delivering more accessible and acceptable care. People centred longitudinal research methods can make a major contribution in our understanding.[32] Serial in-depth interviews are a powerful method that resonates with the clinical aim to provide continuity of contact with patients and their families. The method is also possibly the most affordable in-depth data generation technique, and our experiences suggest that it is also likely to prove acceptable to clinicians.

Lack of awareness and concerns about some theoretical, methodological, and planning considerations currently limit use of this study design. Many of these barriers can be overcome with appropriate planning and groundwork, and although the approach is research intensive, we believe the benefits are well worth achieving. Participants consistently report serial interviews as helpful rather than harmful; researchers also find that such interviewing can be rewarding.[26]

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APPENDIX 2: Co-authored, published journal article two

This is the second of two articles which I co-authored with my colleagues from the Primary Palliative Care Research Group at The University of Edinburgh,

Kendall, M., Murray, S. A., Carduff, E., Worth, A., Harris, F., Lloyd, A., Cavers, D., Grant, L., Boyd, K., & Sheikh, A. 2009, "Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs", British Medical Journal, vol. 340, 196-199 .

URL to multi-perspective paper: http://www.bmj.com/cgi/content/full/bmj.b4122

RESEARCH METHODS & REPORTING

Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs

Marilyn Kendall, Scott A Murray, Emma Carduff, Allison Worth, Fiona Harris, Anna Lloyd, Debbie Cavers, Liz Grant, Kirsty Boyd, Aziz Sheikh

A better understanding of the needs of patients and their carers can help improve services. **Marilyn Kendall and colleagues** describe how to conduct multiperspective studies

Centre for Population Health Sciences: General Practice Section, University of Edinburgh, Edinburgh EH8 9DX

Correspondence to: M Kendall Marilyn.Kendall@ed.ac.uk

Accepted: 3 August 2009

Linked interviews conducted with patients and their informal and professional carers can generate a richer understanding of needs and experiences than the single perspective most commonly used in qualitative studies. Interview dyads or triads, where two or three participants are interviewed as a set or case study, can explore complex complementary as well as contradictory perspectives, and there is considerable scope for using this method in a range of long term conditions.

Based on our experiences of conducting multiperspective studies and drawing on the wider literature, we summarise when researchers might find multiperspective interviews a useful approach, discuss how to use this approach, consider the data that are generated, and highlight potential pitfalls and how to avoid these.[1-5] This paper builds on our previous article discussing the need for longitudinal qualitative approaches.[6] Combining longitudinal and multidimensional interviews can prove particularly valuable.

When are multiperspective interviews appropriate?

Multiperspective interviews are potentially most useful when seeking to

- Understand relationships and dynamics among patients, their families, and professional carers
- Explore similarities and differences in the perceptions of patients and their family and professional carers
- Understand the individual needs of patients, carers, and professionals
- Integrate suggestions for improving services from patients, carers, and professionals.

We have used the approach mainly in the context of pallia-

SUMMARY POINTS

Case linked interviews with patients and their carers can generate a richer understanding of needs and experiences

Such studies can provide practical recommendations about how to deliver services

Serial multiperspective interviewing is particularly valuable in understanding changes over the course of an illness

tive care, where family and professional carers have an important role (table).[1-5] Other researchers have shown the value of a multiperspective approach in diverse clinical areas including the pattern of symptoms in childhood cancer; the couple's experience of breast cancer recurrence and prostate cancer; the complex clinician-patient interactions around requests for physician-assisted suicide; and development of a model of care giving skills for relatives of people with cancer.[7-11]

Dyad combinations typically include husband-wife, mother-child, and patient-carer. Triad combinations, as in a study exploring children's, parents', and professionals' views about tissue donation for research, have been used far less often.[12] In a study of patient-family dyads about information disclosure, the researchers concluded that interview triads would have given broader and deeper information.[13] More recently, another study used interviews with patients, carers, and professionals to explore views about when prognostic discussions should be instigated.[14]

How do you conduct multiperspective interview studies?
Recruitment

Our experiences have highlighted the value of a stepwise approach starting with the patient, then recruiting an informal carer, and finally health or social care professionals. Before patients give their consent, they understand that they will be invited to nominate the family members and professional carers who are most important or central to their care. The aim is to recruit those informants most likely to have relevant information for the study. Consent is obtained from each individual in turn. The aim is to complete a set of interviews over a few days or weeks, ensuring that all participants have the opportunity to reflect on whether they wish to participate and are clearly informed that they are free to withdraw at any time without adversely affecting their or their family's care and support. We found that patients were happy and able to recommend a range of key informal carers and professionals for interview. When approached in this way, the majority of carers were willing to participate.

Data generation

We usually begin by interviewing the patient alone and then the family carer in order to generate separate accounts. However, in about half the cases in our palliative care studies the patient and family carer preferred to be interviewed together. Although this can constrain the discussions, at other times

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patients and carers were able to prompt each other to mention or expand on specific issues or experiences. Interviewing the carer simultaneously also has the advantage of allowing additional insights into the relationship. We typically interview professionals last and have found that telephone interviews, which can easily be recorded using a telephone adaptor, are the most efficient and acceptable method.

Analysis

Analysis proceeds concurrently with data generation, allowing emerging themes and concepts to be reflected on with subsequent participants. Interview transcripts and field notes from each set of patient, family, and professional carer can, however, be analysed as separate case studies and then as groups of case studies. Even a small sample will generate a variety of analytical opportunities, so qualitative software such as NVivo (www.qsrinternational.com) can be useful in organising these data.

If a longitudinal, serial dyad or triad approach is used, analysis may also be undertaken across all first interviews, then across all second and subsequent sets of interviews, or by synthesising data relating to specific key points or transitions, such as interviews with patients approaching the last days of life. By coding within as well as between cases, changes over time linked to particular patients and their associated carers and professionals can be retained and analysed in considerable depth. The context of individual patient journeys is preserved while undertaking the broader thematic analysis.[15] Creation of a matrix linking cases to the coding frame can help writing and interpretation, maximising the strengths of multiperspective data.

What type of findings might you expect?

Understanding of relationships and dynamics
Multiperspective interviews can enhance understanding of interactions such as patient-carer-doctor relationships or provide rich insights into the multifaceted roles of patients within their families and communities and the way in which these serve to maintain their identity. In one case, we conducted interviews with the patient, his wife, a specialist nurse, the church minister, his general practitioner, and an overnight nurse to develop a complex account of the experience of dying at home from lung cancer.[16]

Comparison of perceptions of patients, their family, and carers
Interviews with patient, family, and professional sometimes show concordance in their perceptions. For example, we found that an elderly man with progressive and unstable heart failure described feelings of lack of control and helplessness that were confirmed by his wife, who added that she felt like she was in prison with him. The general practitioner was experiencing similar disempowerment because he felt that he could do very little for such people.[2] In our study of the end of life care needs of South Asian patients in Scotland a participant recounted how he had suffered from discrimination and generally poor care. A linked professional confirmed that this patient's dietary needs had been unmet and his treatment been discriminatory.[3]

However, multiperspective data can also show differing concerns among participants. In our allergy studies, adolescents and parents gave contrasting views of the readiness of adolescents to accept responsibility for managing their condition, with parents far more anxious than adolescents about the dangers of the adolescents' ability to manage risk.[5] In a study of mothers with early breast cancer and their children, although the mothers assumed the children were unconcerned by the diagnosis, the children described themselves as being overwhelmed.[17] We found some health professionals diagnosing clinical depression at the end of

Details of multiperspective interview studies

Aims of study	Patients	Informal carers	Professional carers
To compare the illness trajectories, needs, and service use of patients with cancer and those with advanced non-malignant disease[1]	20 patients with inoperable lung cancer and 20 with advanced heart failure	Spouses, daughters, cousins, warden of sheltered accommodation	General practitioners, district nurses, community palliative care nurse, cardiologist, hospital chaplain
To inform future service developments for people with advanced heart failure[2]	30 patients with advanced heart failure	Spouses, daughters	General practitioners, heart failure nurses, geriatricians, day care staff, community nurses, hospice staff, voluntary workers
To understand the experience of being diagnosed and living with a brain tumour (2005-9)	26 patients with suspected malignant glioma	Spouses, parents, daughters, sisters	General practitioners, clinical oncologists, neurosurgeons, hospital nurses, palliative care nurses, district nurses, allied health professionals, social worker, hospital chaplains
To identify the needs and service use of patients with chronic obstructive pulmonary disease, and to map a framework for an intervention study (2006-9)	20 patients with severe disease	Spouses, daughters	General practitioners, respiratory physicians, community based and hospital based respiratory nurses, nurse from day hospice
To understand end of life care needs of South Asian patients in Scotland and to understand barriers and facilitators to accessing services[3]	25 South Asian patients	Spouses, children	General practitioners, specialist nurses, social worker, oncologist, occupational therapist, hospital manager
To describe the spiritual needs of patients approaching death and to explain how and by whom such needs could best be met[4]	20 patients with advanced malignant and non-malignant disease	Spouses, children, sisters	General practitioners, hospice staff
To explore the psychosocial impact of living with anaphylaxis on adolescents and their parents; their management of the condition; and perceptions of health care provision[5]	7 adolescents with anaphylaxis	Parents	None
To explore perceptions about anaphylaxis and its management and to formulate interventions and evaluate their acceptability to adolescents, parents, and professionals (2008-9)	26 adolescents with anaphylaxis	Parents	Allergy specialists, general practitioners, specialist nurses, school nurses, psychologists, resuscitation officers, dietitians, food and drug industry representatives, voluntary sector staff

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life, when the patient considered the problems to be more existential or spiritual.[6]

Understanding of individual needs of participants

Interviews with multiple people can show different facets of the needs and coping strategies of participants in their role as patient, carer, or professional. Several general practitioners, as well as describing their need for better access to community nursing and social services to support dying patients at home, acknowledged that personal stresses and a lack of adequate training in communication were important barriers to effective care.[1]

Suggestions for improving services

Linked interviews not only show the complexity of individual situations and help researchers understand deficiencies in care from different perspectives, they may also contribute to formulating relevant and workable recommendations for improving services. We organised focus groups of key professionals, patients, and carers to discuss our multiperspective interview data and used the discussion to direct formulation of a framework for planning care for people with advanced heart failure.[2][18] Interviews with bereaved carers, for example, provided in-depth accounts of their experiences that could be integrated and compared with those of the professional carers. We have also developed service recommendations by feeding back interview findings to separate groups of professional, patient, and family participants and asking them to comment on potential interventions.

Potential pitfalls and how to avoid them

Recruitment issues

Recruiting carers into a study at around the same time as the patient might seem to add complexity. Although some patients may be less willing to participate if their family carer is also to be interviewed, it can aid recruitment of vulnerable and potentially hard to access patients because the carer moves from being a protective gatekeeper to a participant.[18] Inclusion of patients who may not have an obvious family carer or friend is important, and careful exploration may identify another supportive relationship—for example, a lung cancer patient identified a sheltered housing warden.[1] We have occasionally had difficulty in recruiting busy professionals identified by patients as a key informant, and competing pressures, such as work or caring for a young family can hinder participation by family carers. Flexibility about the place and time of the interview makes refusal unusual.

Patients and carers opting to be interviewed together

Interviewing participants together is appropriate if this has been requested by participants. This can, however, have costs as well as benefits. Hearing the individual voices of the patient and carer adequately and managing information that may be sensitive or personal in the context of a joint interview can be challenging. As most interviews take place in the patient's home, a carer wishing to add information sometimes takes the opportunity for a word alone when showing the interviewer out or, for example, by inviting the researcher to look at the garden. Patients might suggest the carer make a cup of tea, which then allows them to share information they did not want the carer to hear.

When interviews are separate some carers use the patient interview as an opportunity to go out or carry out short social activities. In our brain tumour study we found that some participants chose separate interviews when they had specific issues to discuss or were not coping or communicating well with their carers.

Joint interviews are particularly valuable when patients have cognitive impairment or communication difficulties.[19] Steinhauser has sought to overcome the difficulties of joint interviewing by providing two researchers to interview the patient and carer independently, but care must be taken not to impose separate, time consuming interviews on participants.[20]

Ethical issues

The ethical pitfalls of multiperspective research should be considered at all stages of the study. When interviewing a family or professional carer after the patient, it is often helpful to build on information from the patient interview. However, care must be taken to preserve confidentiality, particularly as carers may be curious or concerned about what has been said. Ethical issues around acting on the basis of research findings may be more acute when areas of concern—for example, about quality of care or relationships—involve or are corroborated by different interviewees. This method places emotional demands on researchers, especially if generating accounts over time, so support and debriefing from senior staff must be available.

Lack of clarity about aims and analytical strategy

Clear aims and analytical methods need to be set out and agreed at the outset because the quantity of data generated can otherwise rapidly prove overwhelming. When conducting a mixture of paired and individual interviews, both separate and joint interviews should be analysed transparently in the context in which they were generated.[21]

Conclusions

To develop personalised whole person care, we need to use patient centred research methods that can capture the multidimensional nature of the illness experience and place this understanding within a familial and health service context. Concerns about the time consuming nature of the data generation and the fact that fewer participants can be sampled have limited the use of this research method. Many of the potential barriers can be overcome with appropriate planning and groundwork. Generating data from different sources can make a major contribution to identifying people's needs and preferences.[22] Such studies elicit users' views about care in the context of their experiences and integrate these with those of professionals to provide practical recommendations about how services might be delivered more effectively.

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Research methods and reporting

Research methods and reporting is for "how to" articles—those that discuss the nuts and bolts of doing and writing up research, are actionable and readable, and will warrant appraisal by the *BMJ*'s research team and statisticians. These articles should be aimed at a general medical audience that includes doctors of all disciplines and other health professionals working in and outside the UK. You should not assume that readers will know about organisations or practices that are specific to a single discipline.

We welcome articles on all kinds of medical and health services research methods that will be relevant and useful to *BMJ* readers, whether that research is quantitative or qualitative, clinical or not. This includes articles that propose and explain practical and theoretical developments in research methodology and for those on improving the clarity and transparency of reports about research studies, protocols, and results.

This section is for the "how?" of research, while the "what, why, when, and who cares?" will usually belong elsewhere. Studies evaluating ways to conduct and report research should go to the *BMJ*'s Research section; articles debating research concepts, frameworks, and translation into practice and policy should go to Analysis, Editorials, or Features; and those expressing personal opinions should go to Personal View.

Articles for Research methods and reporting should include:
- Up to 2000 words set out under informative subheadings. For some submissions, this might be published in full on bmj.com with a shorter version in the print *BMJ*
- A separate introduction ("standfirst") of 100-150 words spelling out what the article is about and emphasising its importance
- Explicit evidence to support key statements and a brief explanation of the strength of the evidence (published trials, systematic reviews, observational studies, expert opinion, etc)
- No more than 20 references, in Vancouver style, presenting the evidence on which the key statements in the paper are made
- Up to three tables, boxes, or illustrations (clinical photographs, imaging, line drawings, figures—we welcome colour) to enhance the text and add to or substantiate key points made in the body of the article
- A summary box with up to four short single sentences, in the form of bullet points, highlighting the article's main points
- A box of linked information such as websites for those who want to pursue the subject in more depth (this is optional)
- Web extras: we may be able to publish on bmj.com some additional boxes, figures, references (in a separate reference list numbered w1,w2,w3, etc, and marked as such in the main text of the article)
- Suggestions for linked podcasts or video clips, as appropriate
- A statement of sources and selection criteria. As well as the standard statements of funding, competing interests, and contributorship, please provide at the end of the paper a 100-150 word paragraph (excluded from the word count) explaining the paper's provenance. This should include the relevant experience or expertise of the author(s) and the sources of information used to prepare the paper. It should also give details of each author's role in producing the article and name one as guarantor.

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APPENDIX 3: Confirmation of ethics approval

Lothian NHS Board

Deaconess House
148 Pleasance
Edinburgh
EH8 9RS
Telephone 0131 536 9000
Fax 0131 536 9009
www.nhslothian.scot.nhs.uk

NHS

Lothian

Lothian Local Research Ethics Committee 03

Deaconess House
148 Pleasance
Edinburgh
EH8 9RS

Telephone: 0131 536 9022
Facsimile: 0131 536 9346

17 July 2008

Mrs Emma Carduff
PhD student
University of Edinburgh
Community Health Sciences
General Practice
20 West Richmond Street, Edinburgh
EH8 9DX

Dear Mrs Carduff

Full title of study:	**Exploring the potential of Qualitative Longitudinal methods for examining the illness experience of people with advanced cancer and organ failure**
REC reference number:	**08/S1103/35**

The Research Ethics Committee reviewed the above application at the meeting held on 16 July 2008.

Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
Application		19 June 2008
Investigator CV	CI	
Investigator CV	various	
Protocol	1	19 June 2008
Covering Letter		19 June 2008
Letter from Sponsor		11 June 2008
Interview Schedules/Topic Guides	1 Patients/Infor mal Carers/Healt h Professional s	10 June 2008
Questionnaire: Patient Outcome Scale	1	11 June 2008
Letter of invitation to participant	1 Health care	13 June 2008

INVESTOR IN PEOPLE

	professional	
Letter of invitation to participant	1 Informal Carer	13 June 2008
GP/Consultant Information Sheets	1 GP	13 June 2008
Participant Information Sheet: Patient Carer Information Sheet	1	12 June 2008
Participant Consent Form: Health/social care professional	1	13 June 2008
Participant Consent Form: Carer	1	13 June 2008
Participant Consent Form: Patient	1	12 June 2008
Participant Consent Form: Consent to contact carers	1	13 June 2008
Final Thank you letter	1	12 June 2008
Thank you letter	1	12 June 2008
Permission to contact/patient contact details	1	12 June 2008
Univ of Edin letter		03 June 2008

Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

The Committee delegated authority to confirm its final opinion on the application to the Chair.

Further information or clarification required

- Patients should be encouraged to discuss the study with their carers before the carer is contacted.
- Please confirm that researcher will be in close contact with the clinic and that they will therefore be up to date with the current clinical state of participants.
- The process for audio recording of interviews and arrangements for their storage and destruction should be clearly explained in the information sheet and an appropriate bullet point added onto the consent form to allow for this.
- Please be aware that another study is planned using a similar client group.

When submitting your response to the Committee, please send revised documentation where appropriate <u>underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates</u>.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 14 November 2008.

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

APPENDIX 4: Participant and carer information sheet

Exploring the illness experience of people with long-term disease PARTICIPANT / CARER INFORMATION SHEET

This is an invitation to take part in a research study. Before you decide if you want 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 others if you wish. Ask us 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?
By conducting a series of interviews, we are looking to find out more about the physical, psychological and social needs of those with long-term illness so that we can better help people in the future. We would like to know about your experiences, the services you have used and how we can better support your needs. We also want to know about how your needs and experiences change over a period of 12 months. It would be valuable to hear the experiences of a carer at home such as a relative or friend and the health professional that is most involved in your care. Therefore, if you agree, the researcher will also approach them for interview. We would like to hear about all your experiences, good or bad, which will help to improve future research and care. This research is being carried out as part of a PhD project.

Why have I been chosen?
You have been chosen as you have either been in hospital, or have attended an out-patient clinic where your doctor or nurse thinks you are suitable for the study.

Do I have to take part?
No, it is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form.

Can I change my mind about taking part?
Yes. If you decide to take part you may change your mind at any time and without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the standard of care you receive either now or in the future.

What will happen to me if I take part?
Meeting the study researcher
If you are happy to take part in the study, the researcher, Mrs Emma Carduff, will contact you. Mrs Carduff will confirm whether you are

suitable for this particular study and if yes will arrange a time and place convenient to you for the first interview.

The first interview
The first interview can be in your own home or at the hospital. The interview will be about how you feel, the treatment and care you have had and any other issues you wish to discuss. Interviews usually last for about 40 – 60 minutes, but you can break off at any time if you feel unwell. If you agree, the interviews will be recorded so that we can be sure that we remember and understand what you say correctly. The recording will not be heard by anyone other than the researchers and will be kept securely at the University of Edinburgh for 5 years when at which time it will be destroyed. You may listen to the recording, or read the transcript if you wish to do so.

Two further interviews over 12 months
The researcher will contact you by telephone every month to see how you're doing and, if you are still willing to take part, will arrange two further interviews. On each occasion we will ask about how your illness affects you and the care and treatment you have received.

Relatives, carers and professionals
If there is someone who helps and supports you at home (a relative or a good friend), or a carer who helps you, or a doctor or nurse who looks after you, we will ask you if we can approach them and invite them to be interviewed as well. These interviews will also be recorded. We will ask them similar questions so that we can understand their point of view as well. We will not speak to anyone without your consent.

Is there anything else you want to know about me?
We would also like your permission for the researcher to review your medical records. This helps us to understand the treatment you have had.

What are the possible benefits of taking part?
The study will not necessarily help you but by helping us to understand your experiences and how they change over time, we hope that patients with similar problems and their families will get the best possible care in the future.

Are there any risks?
No. There are no foreseeable risks. Your treatment will not be affected; we are only asking you to tell us about your condition and the care you receive. There are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action. Any complaints or concerns about this study should be directed to Dr Kendall: Telephone: 0131 650 9235. E-mail: Marilyn.Kendall@ed.ac.uk. The normal National Health Service complaints mechanisms are also available to you.

Will my taking part in the study be kept confidential?

Yes. Your name will not be known to anyone other than the research team and no information will be given to anyone outside this group. Your GP will be informed that you are taking part in the study. If at interview we discover something which we feel either the hospital consultant or your GP should know about, we would discuss it with you and ask your permission to let them know. We will not pass on any information without your permission. At the end of the study, all the recordings will be destroyed.

What will happen to the results of the research study?

The results of the study will be written as a PhD report and published in medical and other academic journals in order to help others in the field understand your needs and ultimately improve future patient care. You will not be identifiable in any of these reports and everyone who takes part in the study will be given a summary of the results.

Who is organising and funding the study?

Emma Carduff is leading the research project with the support of Dr Marilyn Kendall and Professor Scott Murray at the University of Edinburgh. The study is funded by the Economic and Social Research Council and supported by the University of Edinburgh. The study has been approved by the Local Research Ethics Committee in Edinburgh.

What if you have some questions about the study?

If you would like to ask any questions about participating in the study you can contact Mrs Emma Carduff 0131 650 3209 or email at E.K.Carduff@sms.ed.ac.uk. You may have to leave a message but we will return you call as soon as possible.

(Please note that we can only answer questions about the study – you should discuss any concerns about your illness with your doctor or nurse in the normal way)

What happens now?

If you agree, Mrs Carduff will contact you in a few days to ask if you are interested in taking part in the study. She can answer any questions you may have. If you are not sure, she can phone back another day. If you have decided you do not want to take part, she will not try to persuade you.

**Thank you for taking the time to read this information sheet and please don't hesitate to contact us if you have any questions
Dr Donald Thomson is a GP who is not directly involved with this study, and is available to independently advise you about the study and participation if you should wish (Tel: 0131 650 9456)**

APPENDIX 5: Interview guide for patients and carers

Main Topic	Specific questions or prompts
Setting the scene	
Events to date	When did the problems start? Was there a trigger? How long ago was that? When were you told what was wrong? How did you cope with that? Have you been in hospital? What was it like to be hospital?
Current situation	How are you feeling at the moment? Are there any current problems? What are the contributing factors to these problems? How could these problems be overcome?
Service Provision	
Services	What services do you use? When did these start? How were you made aware of these services? What are your experiences of these services? Are there services that you are aware of that have not been offered or discussed with you? How did you hear about these services? In what way do you think they would be useful for you?
Key professionals	Who are the key health and social professionals involved in your care? Who is the pivotal professional carer? How long have these people been involved in your care? What is their role? Do you feel they adequately understand you needs? If not, how could this be improved?
Home carers	Who looks after you at home? What support (financial and others) do they receive? How do you feel about this?
Needs	
Physical needs	What are your main physical problems? How do these affect your everyday life? How are these problems dealt with in the community? Do you feel they are dealt with appropriately?
Psychological needs	How are you feeling in yourself at the moment? How does this compare with before you became ill? Do you ever feel depressed or low? What are your current worries?
Spiritual needs	How do you cope with your illness? Does anything/anyone help you cope? What do particularly value in life? Do you ever think about the future? Would you describe yourself as a spiritual person?
Social needs	Do you still manage to get out and about? Do you see your friends?
Communication and understanding	
Understanding of disease	What do understand about your illness? Can you tell me what the problem is? Do you like to ask the doctors/nurses questions about your illness? Do you understand what your medicines are for? Do you understand the tests you have had and what they were for?
Communication with professionals	How do you find talking to your doctor/nurse? Do you generally understand what they say to you? Do you like to ask questions? Have you been given the opportunity to ask question? Is there anything specific that the doctor/nurse has done to help you understand your illness? Is there any one professional that you feel understands your situation particularly well? Why do you think this is?
Communication with relatives	Do you often talk to your relatives about your condition? How do you find this? How do you think they find this? Is there anyone in particular that you talk to about your illness? Do you worry about talking to your relatives?
Suggestions for the future	
Future care	How do think we could improve care for people with your illness? Do you think there are any major problems with the current provision of services? Is there anything that would be particularly good for you or your carers?

APPENDIX 6: Patient consent form

> **Exploring the illness experience of people with long-term disease**

CONSENT FORM: Patient

Please initial

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my medical care or legal rights being affected	
I agree that if I have to withdraw from the study for any reason my data up to that point may be used in the results of the study	
I understand that the study will involve me participating in up to 3 interviews over 12 months and that these interviews will be audio-recorded and kept securely, at the University of Edinburgh, for 5 years.	
I agree to the researcher telephoning me once monthly to review my progress	
I agree to my GP being informed of my participation in the study	
I give the research team permission to access my medical notes	
I agree to take part in the above study	

_____   _____   _____
Name of participant   Date   Signature

_____   _____   _____
Researcher   Date   Signature

APPENDIX 7: Informal carer consent form

Exploring the illness experience of people with long-term disease

CONSENT FORM: Carer

Name of Researcher: Mrs Emma Carduff

Please initial

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without affecting the medical care or legal rights of the person I care for	
I agree that if I have to withdraw from the study for any reason my data up to that point may be used in the results of the study	
I understand that the study will involve me participating in up to 3 interviews over 12 months and that these interviews will be audio-recorded and kept securely, at the University of Edinburgh, for 5 years	
I agree to take part in the above study	

_____   _____   _____
Name of participant   Date   Signature

_____   _____   _____
Researcher   Date   Signature

Thank you for helping us with this study.

APPENDIX 8: Coding frameworks for thematic analysis from time 1, time 2 and time 3

TIME 1	TIME 2	TIME 3
CARER ISSUES	NEW NODES T2	NEW NODES T3
Carer allowance	Changes	Cultural issues
Carer perception of illness	Psychological status	Experience of participating in the research
Examples carer telling story	Quality of life	feeling autonomous
Experiences of being a carer	Embodiment	feels unsupported
Fear	Family involvement	Life goes on
Relationship with carer	Protecting loved ones	loss of self
Role - CARER	talking about death to family and friends	loss of self confidence
COMMUNICATION	Feelings	palliaitve care input
Communication and information provision	Abandonment	Reasoning
Disclosing the diagnosis	Feeling needed	reiterating diagnosis story
Mentoring other cancer sufferers	Feels responsible	reliant on others
Finance	Hopelessness	Seeking information
METHODOLOGY	Just like everyone else	The meaning of home
good quotes	Lucky	uncertainty
Metaphors	Maintaining autonomy	CARER ISSUES
Questions to me from participant	uncertainty	COMMUNICATION
Use of evalutation statements	Victimisation	Finance
use of visual narratives	Life experiences	METHODOLOGY
Palliative - in vivo code	CARER ISSUES	NEW NODES 2
Palliative terminal incurable	COMMUNICATION	Palliative or terminal - words_HOSPICE
PERSONAL RESPONSIBILITY	Finance	PERSONAL RESPONSIBILITY
Being a good person	METHODOLOGY	PHYSICAL
Participant parameters	Palliative or terminal - words_HOSPICE	PSYCHOLOGICAL
Fitness before the illness	PERSONAL RESPONSIBILITY	SERVICE PROVISION
PHYSICAL	PHYSICAL	SOCIAL
Cancer Journey	PSYCHOLOGICAL	SOCIETAL THEMES
Acute episodes of illness	SERVICE PROVISION	SPIRITUALITY
Clinic appointments	SOCIAL	TEMPORAL THEMES
Current problems	SOCIETAL THEMES	
Factors contributing to the experience	SPIRITUALITY	
Malignant or non-malignant	TEMPORAL THEMES	
When the problems started		
DIAGNOSIS		
Hunch		
Initial Diagnosis		
Metastatic diagnosis		
Diagnostic tests		
Illness career		
Treatment		
Experience of chemotherapy		
Side-effects of chemotherapy		
Surgery		

TIME 1	TIME 2	TIME 3
PSYCHOLOGICAL		
Coping strategies		
Acceptance		
Denial		
Having a sense of purpose		
Hope		
Maintaining Control		
Stoicism		
Emotional response to illness		
Psychological impact of diagnosis		
Why me		
SERVICE PROVISION		
Health professionals - Role and relationship		
Health Services		
Primary care		
Secondary care		
Social services		
SOCIAL		
Employment		
Social wellbeing		
Support from friends and family		
SOCIETAL THEMES		
Body image		
How people wish to be viewed by others		
Perception of self		
Gender		
Medicalisation		
Preconceptions about cancer		
Cancer and labelling		
Friends or family with illness		
General perception		
SPIRITUALITY		
Fatalism		
Meaning of life		
Spiritual wellbeing		
TEMPORAL THEMES		
Reflections on the past		
The future		
Time		

APPENDIX 9: Example of OSOP method of thematic analysis

PSYCHOLOGICAL ISSUES TIME 1.

In front of family — strategies to deal with them

acknowledge it and realise it's ok — eg is there someone I can talk to? go out for a walk

Codes	Issues discussed	Ref containing theme	No of quotations with theme	THEMES
Emotional response to illness	Ups + downs	MM, P04, P06, P11, P13, P14, P15, P16		The need to be positive and fight the cancer was evident, particularly in the early stages
	Triggers to downs — WHAT ARE THEY?	P4, P14		
	Unable to plan ahead	P04, P05, P13, P14		Changes in mood were the common and participants are required to develop their own coping strategies in response
	Positive	P01, P14		
	Fight it	P16		
	Channel one	P14		
Psychological impact of diagnosis	Prognosis ?	P05		IMMEDIATE → Why me? Seeking understanding as to why it has happened and for what the prognosis might be. People described being shocked not just by the diagnosis but also by the extent of disease.
	Trying to understand how it happened	P06, P07, P11		
	Shock			
	Didn't involve me	P14, P14		
	So young			
	Why me? ? Been a good person, looked after my body, it's unfair			
	Why not me?			

not done this — might be better picked with other diagnosis/illness