

**EXPERIENCES OF PATIENTS AND
OF PARTNERS OF PATIENTS WITH
A RECURRENCE OF COLORECTAL CANCER:
A QUALITATIVE LONGITUDINAL STUDY**

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Abstract

Colorectal cancer is the fourth most common cancer type in the UK. Following treatment, many patients will recover and be considered cured. However, this is not the case for all patients and some will face a recurrence of their cancer. This PhD aimed to explore the experiences of patients and partners of patients when colorectal cancer recurs.

A meta-ethnography and literature review were conducted to examine the existing research evidence on the experiences of patients and of partners, respectively, at the time of recurrence. While these reviews provided some insights, they also highlighted the lack of studies exploring this important phase in the cancer journey.

Interpretative Phenomenological Analysis (IPA) was chosen as a methodology to explore in depth the experiences of patients and partners. A longitudinal design was used to capture changes in participants' experiences. Analysis of interviews with six patients with colorectal cancer recurrence and five partners revealed that the initial diagnosis was an important framework for making sense of the diagnosis of recurrence. Specifically, participants compared the treatment options, quality of care and prognosis at the time of recurrence to those at initial diagnosis which, in turn, could either magnify or lessen their distress. Patients faced challenges in sharing their experience, including their emotions and information on their illness. Partners also struggled to share their experiences with other people, but these challenges were mainly related to the physical and emotional burden of caring. Finally, the study also highlighted that the diagnosis of recurrence disrupted previous rhythms of life for both patients and partners. While patients' accounts focused on ways of negotiating the place of cancer in their lives within the context of coping with physical suffering, partners also grieved the loss of a previous relationship with a patient.

This PhD captures the difficult experience of colorectal cancer recurrence for patients and partners, and the complex psychological processes that underpin this experience. The findings have clinical implications regarding information and supportive care provision and may help to inform further development of health care services for patients with colorectal cancer recurrence and their partners.

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Chapter 1. Introduction

1.1 Introduction

In the last few decades, the main focus of cancer care from both policy makers and researchers was cancer survivorship. Only recently have, issues related to living with the active disease received the attention they deserve. One example of this is the establishment of The National Cancer Survivorship Initiative, which defined the scope of its work as “Living Well With and Beyond Cancer”. In 2011, this Vision Document highlighted Active and Advanced Disease as a priority (Department of Health et al., 2010). The document recognised that an increasing number of people are living longer with active and advanced cancer, and thus also recognized the importance of understanding the health care and support needs of patients and their carers to ensure positive experiences of the health care system.

Colorectal cancer is the fourth most common cancer type in the UK (Cancer Research UK, 2014a). A number of patients with colorectal cancer will recover following their treatment and be considered cured. However, this is not the case for all patients; some patients will face cancer recurrence. Little is known about the experiences of patients and partners during this difficult time. This PhD addresses these gaps in knowledge by exploring over time the experiences of patients and partners when cancer recurs.

This chapter provides an overview of the key clinical features of colorectal cancer and the psycho-social impact of these issues on patients and partners. At the end of this chapter, I will provide an overview of all the chapters in this PhD.

1.2 Colorectal cancer- clinical picture

1.2.1 Importance of colorectal cancer

Colorectal cancer occurs when cancerous cells form in the tissue of colon and/or rectum (Cancer Research UK, 2013b). Similar numbers of new cases of colorectal cancer are identified per year for men and women: 23,200 and 18,400 respectively (Cancer Research UK, 2014a). The incidence of colorectal cancer is related to age with 95% of those diagnosed being over 50 (Cancer Research UK, 2014b). Two-thirds of all colorectal cancers are colon cancers and the remaining one-third are rectal

cancers. Whereas the incidence of colon cancer is almost equal across sexes (53% for men and 47% for women), approximately 60% of cases of rectal cases are diagnosed in men (National Institute for Health and Care Excellence- NICE, 2014).

Colorectal cancer is often referred to as a Western disease because the incidence rates seem to be higher in more industrialised countries (Labianca et al., 2010). The most known risk factors include poor diet and lack of physical activity (Cancer Research UK, 2014a). However, some hereditary syndromes as well as inflammatory bowel diseases are also known to be contributing factors (Hall, 2007).

1.2.2 Mortality/survival rates

Colorectal cancer is the second most common cause of cancer deaths in the UK (Cancer Research UK, 2014a), and over 16000 patients in the UK die from it each year (Cancer Research UK, 2014a). It is the third most common cause of cancer death in men and the second most common in women. The most recent statistics show similar 5-year survival rates across sexes: 58% for women and 59% for men (Cancer Research UK, 2014a). However, if detected early, 5-year survival could be as high as 90% (Cancer Research UK, 2014a).

1.2.3 Diagnosis

1.2.3.1 Diagnosis as a result of screening

Screening is an important tool in the early detection of colorectal cancer (Weitz, 2007). The National Bowel Cancer Screening Programme was introduced in the UK in 2006 after two pilot programmes, which tested its effectiveness and acceptability. Bowel cancer screening is the first screening programme offered to both men and women. In England, the programme targets those aged 60 to 69 years old. At the moment, screening involves the use of a faecal occult blood (FOB) testing kit for blood in bowel motions. On average, 2 out of 100 people will have an abnormal result which will need to be investigated further (Department of Health, 2012). These patients will be offered colonoscopy. However, not all patients who have an abnormal result will be diagnosed with cancer (Department of Health, 2012). By introducing bowel cancer screening, the UK has joined other European countries as well as Canada, USA and Australia (Payne, 2007). Since screening for colorectal cancer is often able

to detect precancerous diseases, which significantly increases survival rates, it can potentially be a very effective programme for reducing the mortality of cancer (Labianca et al., 2010).

1.2.3.2 Diagnosis via self-referral

Symptoms of concern include rectal bleeding, a change in bowel habit lasting over 6 weeks, signs of anaemia or obstructive symptoms (Hall, 2007). The process of diagnosis can include biochemical tests, colonoscopy, CT scans and biopsy (Hall, 2007). The lungs and liver are often scanned as well to eliminate the possibility of metastatic disease (Cunningham and Lindsey, 2007). Colonoscopy still remains the gold standard for the diagnosis of colorectal cancer (Weitz, 2007). Once diagnosed, the staging of colorectal cancer is described using either Duke's or Tumor, **N**ode, **M**etastases (TNM) staging systems. For both TNM (0-4) and Duke's systems (A-D) there are four stages of the disease with 4th stage and D stage meaning that cancer has spread to different parts of the body (Cancer Research UK, 2013a).

1.2.4 Treatment

Once diagnosed, patients are usually faced with a number of treatment options such as surgery, chemotherapy or radiotherapy or a combination of these. The treatment regime is dependent on a number of factors such as stage and grading of the illness as well as general health of the patient (Cancer Research UK, 2013d). The decision regarding the optimum treatment for each patient is usually discussed at multidisciplinary team meetings (Cunningham and Lindsey, 2007), where people from different disciplines meet to discuss the treatment options and management of the patient (Department of Health, 2004).

The majority of patients with an initial diagnosis of colorectal cancer will be offered treatment with curative intent. Surgery is the main treatment and involves removing the part of the bowel/rectum that contains cancer cells. The type of operation and how much of the tissue is removed will depend on where the tumour is located. This in turn will have an effect on the recovery processes (Cancer Research UK, 2013c). For patients whose cancer is detected early, keyhole surgery may also be a possibility which may offer a shorter hospital stay and quicker recovery (Cancer Research UK, 2013c)

The stage of cancer may also influence whether the patient will be offered chemotherapy. People with stage A are unlikely to have chemotherapy before or after surgery as the risk of recurrence is relatively low. There is lack of clear clinical guidelines and research evidence whether chemotherapy should be used for patients with stage B and this is assessed on an individual basis (Hall et al., 2000). For patients who have been diagnosed with stage C colorectal cancer, chemotherapy is usually used to reduce the risk of cancer coming back (Cancer Research UK, 2013e). Patients with rectal cancer may also need to have radiotherapy either before or after surgery, while radiotherapy is not a common treatment for colon cancer (Cancer Research UK, 2013e).

While some patients are able to recover from the treatment and resume their previous level of functioning, others experience ongoing symptoms. These symptoms may include tiredness, sleep problems, or loss of weight (Dunn et al., 2006, Houldin, 2007, Simpson and Whyte, 2006). In addition to these problems, which are also experienced by other cancer patients, patients with colorectal cancer often also experience problems with their bowels (Dunn et al., 2006, McCaughan et al., 2010, McCaughan et al., 2011, Nikoletti et al., 2008) including diarrhoea, constipation and incontinence (Landers et al., 2012).

Bowel problems may lead to changes to lifestyle with some patients reporting difficulties with going out in fear of not being able to access toilet facilities (Dunn et al., 2006). Some feel that planning ahead and knowing the location of toilets provides some reassurance, while others are only able to deal with their bowels in the comfort of their homes (Rozmovits and Ziebland, 2004, McCaughan et al., 2011). Other studies also highlight how treatment and subsequent symptoms have affected patients' appearance and consequently their self-image (Hubbard et al., 2010, Dunn et al., 2006).

The impact of symptoms following treatment on the partners can also be significant. Partners often report feeling overwhelmed with patients' physical symptoms, such as incontinence or unpredictable bowel movements (Ohlsson - Nevo et al., 2012). They are often responsible for practical support such as changing dressings but also feel unprepared for this (Ohlsson - Nevo et al., 2012). Some partners also describe some changes to their intimate relationship and the physical impact of increased

responsibilities such as difficulties with sleeping and appetite (Houldin, 2007).

If a large amount of bowel or rectum has to be removed, to facilitate the healing of the wound, patients may also need to undergo a colostomy which involves having a stoma bag which will collect bowel motions. For some patients this stoma will be a temporary solution and they will have a stoma reversal operation sometime after the initial surgery. For others, this may not be possible because of the amount of tissue removed and the location of the tumour. These patients may need a permanent stoma (Cancer Research UK, 2013c). Patients who have a stoma report overall poorer quality of life and more symptoms, particularly in relation to sexuality in comparison to patients without a stoma (Nugent et al., 1999). Studies highlight that patients with a stoma often found the experience of having a stoma as deeply humiliating, especially if it led to dependence upon family members (Emslie et al., 2009, McCaughan et al., 2010). In contrast, some studies highlight that although patients described their feelings of disgust and uncertainty around a stoma, they also felt that it was important to accept it to be able to carry on and tried to focus on the fact it allowed them to be alive (Sahay et al., 2000). Patients with a stoma also report changes to their social and professional lives and experience difficulties in returning to their previous activities (Sprangers et al., 1993). These changes seem also to be related to a distorted body image as a result of having a stoma which can even worsen with time (Sharpe et al., 2011). Fears about stoma leakage may result in withdrawal from social activities as well as altering intimate relationships (Persson and Hellström, 2002).

Similarly to patients, partners are also affected by patients' having a stoma (Oberst and James, 1985) with some accepting it as part of the patient and some seeing it as repulsive (Ohlsson - Nevo et al., 2012). A recent systematic review highlighted the challenges faced by the partners of colorectal cancer patients with a stoma (Danielsen et al., 2013). Firstly, spouses reported that they often lacked information and support from health care professionals in how to help the patient manage the stoma. They also wanted to know more about the implications in relation to, for example, travelling and socialising. Secondly, sexual life seems to be affected as a number of couples did not resume their sexual life as a result

of the patient having a stoma. Finally, some studies described the limitations and changes imposed on the partner's social life as a result of the patient having a stoma, and the difficulties they experienced in accepting these limitations and changes. These were related to the difficulties partners had in leaving the house as well the need for them to take on greater responsibility in the household. Some studies also reported that as patients were getting stronger and the threat of death was diminishing, partners seemed to report more anxiety and frustration with the stoma (Persson et al., 2004). For some, these difficulties seem to decrease and partners reported an acceptance of the stoma as they perceived it as lifesaving (Persson et al., 2004).

1.2.5 Fear of recurrence and follow-up system

If treatments are successful, patients are considered to be in remission. When in remission, patients are usually followed-up by their hospital team and/or GP (Cancer.Net, 2010). The follow-up system can include any combination of outpatient appointments, haematological as well as radiological evaluations and, colonoscopy. There are a number of reasons for follow-up programmes. The main reason is to detect whether cancer has recurred, which is especially relevant for patients who are asymptomatic, while monitoring for any side-effects and problems related to treatment and providing psycho-social support to patients is also important (Weitz, 2007, Scholefield, 2002).

While follow-up appointments offer them some reassurance, patients still experience fears of recurrence. Studies suggest that there seems to be a great variability in the extent to which patients worry about cancer recurrence, with studies reporting the prevalence of fear of bowel cancer recurrence between 7-50% (Baker et al., 2005, Deimling et al., 2006, Krouse et al., 2009). Qualitative studies also mirror these differences with some studies indicating that it may be a major problem for patients while others do not see it as a pressing concern (Taylor et al., 2011, McCaughan et al., 2010). In order to better understand this process, studies also tried to focus on factors predicting greater fears of recurrence. Younger patients were found to perceive their risk of recurrence as greater (Mullens et al., 2004). Also, fears of bowel cancer recurrence have been found to decrease with time, with bowel patients up to two years following

diagnosis experiencing greater fear of recurrence than those who received their diagnosis between two and four years ago (Mullens et al., 2004). Patients seem to use a number of different strategies to deal with these fears. While some may engage in constant monitoring of their bodies to gain some reassurance (Taylor et al., 2011), others may try to manage their fears by distracting themselves (Nikoletti et al., 2008). Finally, some studies also highlighted that to minimise their perceived risk of recurrence, patients may make changes to their lifestyle by changing their health (Mullens et al., 2004, Sahay et al., 2000).

The issue of fear of recurrence in partners has received little attention and it is difficult to estimate the extent of the problem. However, qualitative studies have highlighted that while some partners, similarly to patients, seem to be preoccupied with fear of recurrence for extended periods of time following the completion of the treatment, some perceive patients as cured (Ohlsson - Nevo et al., 2012, Northouse et al., 1999). Follow up appointments seem to be a particular reminder of the potential threat of another cancer. For those partners who were not able to be involved in the care of the patient, because of barriers imposed by either patients or health care professionals, the fear of recurrence seemed to be greater (Persson et al., 2004).

1.2.6 Bowel cancer recurrence

If after a period of being disease free, cancer comes back, it is regarded as a recurrence (Cancer.Net, 2010). Bowel cancer recurrence can be described as local or distant recurrence. Local recurrence occurs when the cancer cells regrow in and around the area of the original cancer site (tumour bed). If the cancer cells spread through the blood stream or lymphatic system and appear in different parts of the body than the initial tumour it is then called distant recurrence (Guyot et al., 2005).

1.2.7 Incidence rates- recurrence

It is difficult to find UK data regarding the incidence of bowel cancer recurrence, and ensuring that recurrence information is recorded is now on the agenda in the Active and Advanced Disease domain of the National Cancer Survivorship Initiative. However, data from Europe and the USA highlight that it is a common problem. One American cohort of patients who had received surgical treatment with curative intent found a recurrence rate

of 18% over a 55 month period (Weiser et al., 2008). The main site for bowel cancer recurrence is the liver followed by peritoneal seeding with skin, brain and bone being less frequent metastatic sites (Hall, 2007).

1.2.8 Mortality/survival rates for recurrence

The prognosis following a diagnosis of recurrence of colorectal cancer differs depending whether it is a local or distant recurrence. Recent data from the French Cancer Registry over a 28 year period have shown that the overall one- and five-year survival rates for local recurrence of colorectal cancer were found to be 50.2% and 15.7% respectively, whereas for distant recurrence the rates were 34.5% and 5.5%. Five-year survival rates for colon cancer were significantly higher (52.4%) than for rectal cancer (46.6%) (Guyot et al., 2005).

Being offered curative surgery is a significant predictor for 5-year survival, with survival rates following surgery of 36.1% for local recurrence and 24.0% for distant metastases. Colon cancer patients usually face a better prognosis with 5-year survival rates for both local and distant recurrence of colon cancer being significantly higher than those for rectal cancer (Guyot et al., 2005) The relative risk of death was found to be two to four times lower in patients who had surgery with curative intent in comparison to palliative cancer treatment (Guyot et al., 2005).

1.2.9 Treatment for recurrent cancer

Treatment depends on a number of factors including the type (local vs. distant), size and the location of the recurrent cancer (American Cancer Society, 2014). Other factors which are considered are the time since initial diagnosis, the type of treatment received at the initial diagnosis as well as patient's response to it and the potential effects of the treatments on the individual's quality of life (American Cancer Society, 2014). For local and distant recurrence, surgery is usually the best option which is likely to be followed by the chemotherapy (American Cancer Society, 2014). For some people, the aim of the surgery could be to cure the cancer. If surgery is not possible, chemotherapy is usually offered to reduce the size of the tumour. If that is successful, surgery can also be offered subsequently. Similarly to the initial treatment, some patients may need to have either a temporary or permanent stoma after the surgery (National Cancer Institute, 2014).

In recent years, the way colorectal cancer recurrence is managed has changed (Scheele and Altendorf-Hofmann, 1999). A recent French study revealed that rates of surgeries with curative intent between 1985-1993 and 1994-2003 were much higher than in the previous years (1976-1984) (Guyot et al., 2005). In general, surgery with curative intent is more common for colon cancer than for rectal cancer. Furthermore, patients with a local recurrence of colon cancer might be more likely to undertake surgery with a curative intent than patients with a local recurrence of rectal cancer (Guyot et al., 2005). Those under the age of 75 are also more likely to be offered treatment with a curative intent (Guyot et al., 2005). Overall, the options available to patients at this stage might be similar to those at the point of the initial diagnosis, but the intent of the treatment or the role of a particular treatment in the overall treatment plan is usually quite different (American Cancer Society, 2014).

1.3 Thesis structure

This chapter has provided an overview of the clinical picture of colorectal cancer recurrence, highlighting that it is a significant problem. It has also described a number of difficulties, which patients and partners commonly experience when diagnosed with colorectal cancer, including dealing with symptoms, dealing with a stoma, as well as fear of recurrence. Colorectal cancer recurrence is common and is an important challenge for both patients and their partners. Following this introductory chapter, Chapter 2 and 3 provide a more detailed insight into the current evidence regarding patients and partners' experiences of cancer recurrence. More specifically, chapter 2 is a meta-ethnography of qualitative studies exploring the experiences of patients with cancer recurrence (at any cancer site). Given the small number of studies exploring the experiences of partners when a patient's cancer recurs, the literature review on partners includes both quantitative and qualitative evidence in the area of advanced cancer (recurrence and advanced cancer diagnosed from the beginning). Based on the current evidence, the gaps are identified and presented at the end of Chapter 3 along with the research questions.

Chapter 4 provides a description of the methodology chosen for this study, namely Interpretative Phenomenological Analysis (IPA) and the rationale

for choosing IPA. The chapter then goes on to provide a description of the sample, methods of data collection and analysis.

Chapter 5 and 6 report on the findings from qualitative longitudinal interviews with patients' and partners' study respectively. Three themes have been identified for each group. Each theme is divided into two sections: Part A (describing the particular theme) and Part B (discussing that theme in relation to the current research evidence).

Finally, Chapter 7 is an overall discussion of the project. It summarises the key findings and the contributions to existing theories. It also discusses the clinical implications of the project, alongside its strengths and limitations and recommendations for future research.

Chapter 2: Patients' experience of cancer recurrence: a meta-ethnography

2.1 Introduction

This chapter presents a synthesis of qualitative studies exploring the experiences of patients when their cancer comes back with the aim of drawing together the current evidence while also identifying research gaps. Two narrative reviews by Warren have previously explored the qualitative and quantitative evidence in relation to experiences of cancer recurrence of breast cancer patients (Warren, 2009, Warren, 2010) while Vivar et al. (2009) conducted a narrative review, which focused on issues in the survivorship phase (e.g. fear of recurrence) and recurrence for patients diagnosed with any cancer and their families. They highlighted that cancer recurrence is a critical point in cancer trajectory as it brings a realisation for patients and their families that cure has not been achieved, which in turn magnifies the uncertainty of the situation. They also show the challenges of facing treatment again and anxieties related to that (Vivar et al., 2009, Warren, 2009, Warren, 2010).

One of the main issues raised by these reviews is the level of distress experienced by patients at this stage. Studies reported that up to 40% of patients with a recurrence of their cancer may suffer from distress (Okamura et al., 2000) and up to 20% from a psychiatric disorder (Okamura et al., 2005). Studies have compared the levels of distress between patients with initial diagnosis and recurrence and whilst some found that patients with recurrent disease reported more distress (Cella et al., 1990), others highlighted that patients were no more distressed than when those following initial diagnosis. Oh et al. did report however that patients with metastatic recurrence experienced more distress than those with only locally advanced disease (Oh et al., 2004). The reviews also highlighted that younger patients and those whose recurrence was diagnosed less than 24 months after the initial diagnosis were more distressed (Okamura et al., 2000). However, as highlighted by Burnet and Robinson (2000), while these studies demonstrate that cancer recurrence is clearly a very difficult time for patients, even more than the initial diagnosis, the focus should not be on merely levels of distress but on specific challenges related to this stage in cancer journey. A synthesis of qualitative studies looking at the

experiences of patients with cancer recurrence of any type can illuminate these challenges.

As mentioned before, the three narrative reviews did include qualitative studies. However, Warren's reviews did not mention three studies with breast cancer patients included in the meta-ethnography described in this chapter, while Vivar's review (2009) only included two studies which were identified as part of this meta-ethnography. This demonstrates a need for bringing together qualitative literature on cancer recurrence from the perspective of patients.

2.2 Methods

Meta-ethnography is one of the interpretative methods available to bring together evidence from qualitative research. It has been suggested that meta-ethnography is most suitable when looking at individuals' experiences (Atkins et al., 2008). The meta-ethnography presented here followed the approach developed by Noblit and Hare in education (Noblit and Hare, 1988) and further developed in health care research (e.g. Toye et al., 2014a, Toye et al., 2014b). Noblit and Hare (1988) identified seven phases in the meta-ethnography process. Phases one and two relate to identifying the research area to focus on and creating the search strategy, followed by the critical appraisal of the identified studies, while phases three to seven are directly related to synthesising and presenting the synthesis.

2.2.1 Systematic search

Three electronic databases- Medline, CINAHL and PsycINFO were searched in April 2014. The full search strategy is available in presented in Table 2.2.1. Due to the well-known difficulties of indexing qualitative studies, particular attention was paid to developing a comprehensive search strategy for studies which used a qualitative methodology. The search included studies published between 1994 and April 2014. As the last two decades have seen major changes in cancer treatments and health care services, it was decided to restrict the search to this period. Grey literature was not included. The inclusion criteria were studies that: a) explored the experience of patients with a cancer recurrence and b) used qualitative methodology to gather and analyse results and c) were published in English.

Table 2.2.1: Search terms

Terms	
1	(maximum variation or snowball).mp.
2	(thematic\$ adj3 analys\$).mp.
3	(participant* adj3 observ*).mp.
4	(nonparticipant* adj3 observ*).mp.
5	(non participant* adj3 observ\$).mp.
6	(structured categor* or unstructured categor*).mp.
7	action research.mp.
8	(audiorecord* or taperecord* or videorecord* or videotap*).mp.
9	9. ((audio or tape or video*) adj5 record*).mp.
10	10. ((audio* or video* or tape*) adj5 interview*).mp.
11	(content analy* or field note* or fieldnote* or field record* or field stud*).mp.
12	(qualitative* or ethno* or emic* or etic or emic or phenomenolog*).mp.
13	(hermeneutic* or heidegger* or husserl* or colaizzi* or giorgi* or glaser or strauss).mp.
14	(van kaam* or van manen or constant compar*).mp.
15	(focus group* or grounded theory or narrative* or lived experience* or life experience*).mp.
16	(theoretical sampl* or purposive sampl* or ricoeur or spiegelber* or merleau ponty).mp.
17	IPA.mp.
18	interview*.mp.
19	biographical.mp.
20	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
21	adjustment.mp.
22	perception.mp.
23	"information need*".mp. [mp=ti, ab, ot, nm, hw, kf, px, rx, ui, tc, id, tm]
24	"supportive need*".mp.
25	"supportive care*".mp.
26	experience*.mp.
27	psycho-social.mp.
28	psychosocial.mp.
29	psycholog*.mp.
30	social.mp.
31	adaptation.mp.
32	information*.mp.
33	21 or 22 or 23 or 24 or 25 or 26 or 27 or 28
34	(cancer* or carcinoma* or malignan* or tumour or tumor or neoplasm*).mp.
35	(secondar* or recur* or relapse* or metasta* or advanced).mp.
36	34 and 35
37	20 and 33 and 36
38	limit 37 to English language
39	limit 38 to humans
40	remove duplicates from 39

2.2.2 Critical appraisal

While a number of tools are used in appraising qualitative studies, the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist is the one most commonly used in meta-ethnography (Campbell, 2011). All studies included in this meta-ethnography were appraised using the CASP tool, and then coded using the coding scheme devised by Dixon-Woods: KP (key paper providing rich conceptual insights), SAT (satisfactory paper), FF (fatally flawed) and IRR (irrelevant: not meeting inclusion criteria) (Dixon-Woods et al., 2004). All papers were reviewed by myself and by one of my supervisors. Quality appraisal was conducted to describe the quality of the current evidence. It was decided not to exclude any papers based on quality as methodologically weak papers can still provide rich conceptual insights (Dixon-Woods et al., 2007).

2.2.3 Data extraction and Synthesis- stages 3 to 7

Phase 3 involved reading the articles selected for the synthesis and further familiarisation with them. As part of this process, relevant information including background, methods and results were extracted.

Stage 4 was focused on identifying data for meta-ethnography. As part of this process, first order constructs (quotes from the participants) and second order constructs (key concepts and themes and their interpretation by the paper's authors) were extracted by myself and one of the supervisors independently. The aim of extracting first order constructs is only to provide an illustrative quote, as it is the second-order constructs that form data for meta-ethnography. As pointed out by Toye et al. (2014a), quotes provided under a particular second-order construct are selected by authors and therefore may not illuminate every aspect of it. To aid this process, following Malpass and colleagues (Malpass et al., 2009) a table was created, with each second-order construct from each paper listed alongside the representative quotes from the participants. Each row represented one second order construct from a particular paper.

Stage 5 (translation of the studies) involved looking at how studies were related to each other and required reading each row to consider how the constructs were related. The focus of the translation was not on the names of the second order constructs but rather on the description extracted earlier to see if the constructs were related.

Phase 6 involved generating a conceptual model (third-order constructs). For example, the second order construct: *Diagnosis of recurrence* in the study of Mahon and Casperson (Mahon and Casperson, 1997) and *Emotional reactions* in Griffiths et al. (Griffiths et al., 2008) each contributed to the third order-construct *Experiencing emotional turmoil after diagnosis*. An illustration of the process is presented in Table 2.2.3. The aim here was not only to summarise the data but to create conceptually rich third-order constructs, encompassing the dynamic experience of participants. This synthesis took form the form of a reciprocal translation, which is possible when studies included describe similar findings (Noblit and Hare, 1988).

Table 2.2.3: Example of third-order construct based on second-order constructs

Third order construct	Paper	Second-order constructs	Description of the second-order construct	First order construct (quote from the participants)
Experiencing emotional turmoil after diagnosis	Mahon and Casperson (Mahon and Casperson, 1997)	Diagnosis of recurrence	Participants experienced a variety of symptoms and attributed them initially mainly to non-cancer causes. They described the emotional reactions of being overwhelmed and shocked even though being prepared for recurrence.	<i>I knew all along that it could come back but let me tell you, nothing could prepare you for it. Even though I knew it was happening. I got real lightheaded when doctor told me.</i>

Table 2.2.3 Continued: Example of third-order construct based on second-order constructs

Third order construct	Paper	Second-order constructs	Description of the second-order construct	First order construct (quote from the participants)
Experiencing emotional turmoil after diagnosis	Griffiths et al. (Griffiths et al., 2008)	Emotional reactions	Participants described the emotional impact of diagnosis including shock, devastation, emotional vulnerability and hopelessness. Also experienced intense feelings of shame, often related to feeling a burden on loved ones.	<i>I just felt numb. I was speechless.</i>

2.2.4 Results of the search

The search yielded 2271 abstracts after duplicates were removed. I screened each abstract and two additional reviewers (supervisors) screened a subset (10%) to establish if the paper was 1) a qualitative paper and 2) addressed the topic of interest. This initial screen resulted in 2150 articles being rejected. The remaining 121 were subjected to full text review: 103 were excluded for the following reasons: 32 did not use

qualitative methodology, 49 did not include patients with a recurrence of cancer or did not clarify whether the patients had a recurrence, 13 did not allow extraction of data relevant to patients with a cancer recurrence, 3 did not focus on patients, 2 evaluated interventions and 4 could not be obtained. Following the final stage of the synthesis, one article had not contributed to the meta-ethnography and it was decided to exclude that paper (Rose et al., 2013). The aim of this article was to explore how patients with a recurrence of ovarian cancer experience humour. This proved to be too narrow in its focus to contribute to this meta-ethnography. Figure 2.2.4 provides an overview of the studies included in this meta-ethnography.

A total of 17 articles were included, based on 15 data sets. Two research groups: Chunlestkul et al. (Chunblestkul et al., 2008a, Chunlestkul et al., 2008b) and Ekwall et al. (Ekwall et al., 2007, Ekwall et al., 2011) each did a study on which they published two papers each. Additionally, Ekwall and colleagues (Ekwall et al., 2014) re-interviewed a sub-sample of patients from two previous studies three and five years later, which was published as a separate paper. A description of all included studies is presented in Appendix 1.

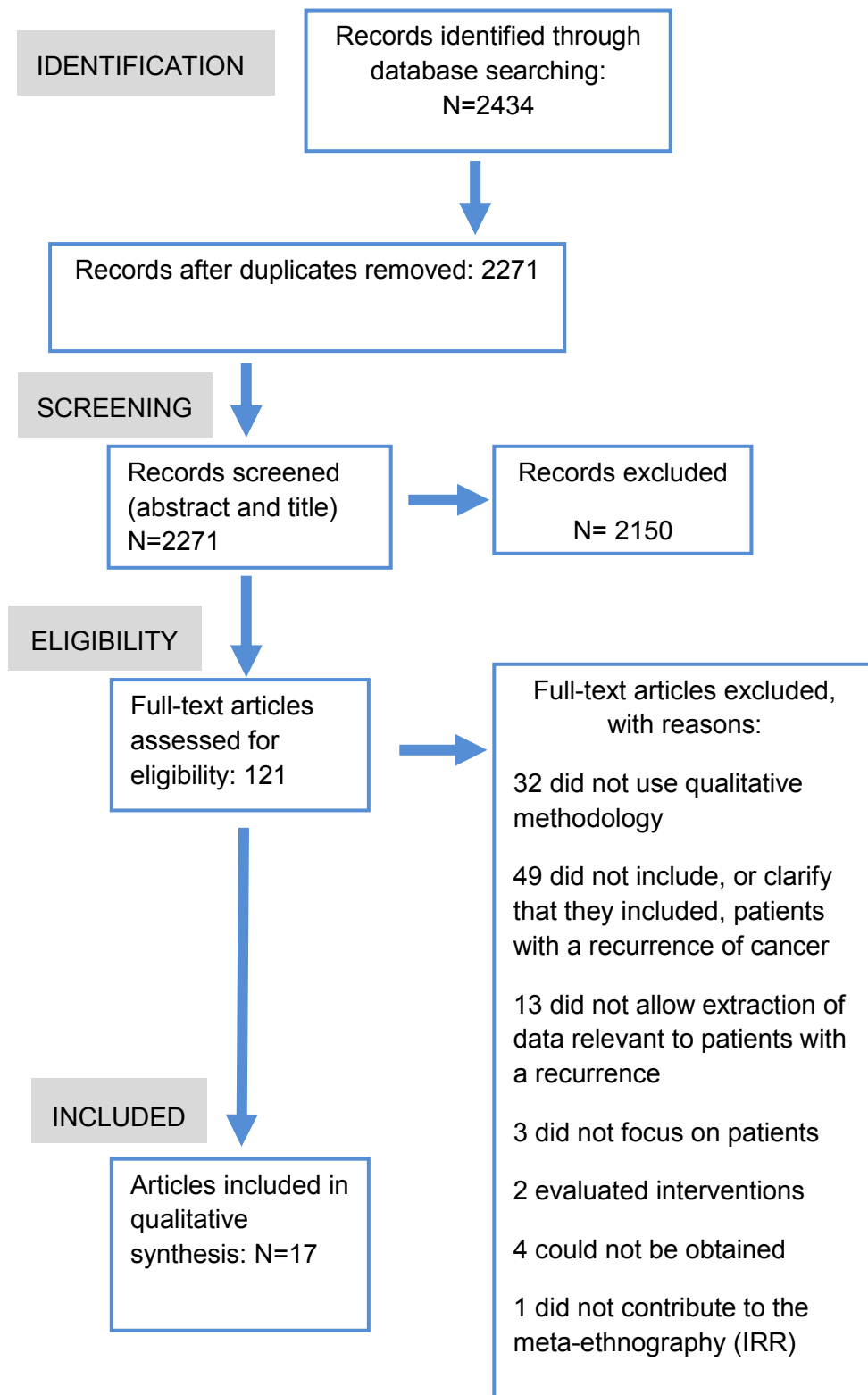


Figure 2.2.4 PRISMA flowchart

2.2.5 Critical appraisal

The papers included in the review were of varied quality. Only seven were coded as a key paper, while 11 were rated as of satisfactory quality. No papers were rated as fatally flawed. A number of papers lacked a detailed description of the methodology, presented purely descriptive findings or failed to discuss the way the values and assumptions of a researcher may have shaped the findings. Studies represented a variety of analytical approaches including Phenomenology, Grounded Theory and Content Analysis. In some papers, the analytical approach used was not made explicit. Studies were published between 1997 and 2014 and were conducted in UK, Europe (Sweden) and North America (Canada and USA). The main method of data collection was individual interview. Studies included patients with a range of cancer types with breast and ovarian cancer being most common.

2.3. Results

The synthesis identified wide-ranging ways in which a recurrent cancer impacted on participants. The third-order constructs developed to capture these were: *Experiencing emotional turmoil after diagnosis*, *Experiencing otherness*, *Seeking support in the health care system*, *Adjusting to a new prognosis and uncertain future*, *Finding strategies to deal with recurrence* and *Facing mortality*.

2.3.1 Experiencing emotional turmoil after diagnosis

Diagnosis of recurrence was an emotional experience, generating a range of responses including shock, fear, anger, devastation or hopelessness (Ekwall et al., 2007, Griffiths et al., 2008, Howell et al., 2003, Mahon and Casperson, 1997, Sarenmalm et al., 2009). In two studies of patients with a recurrence of oral and ovarian cancer, feelings of shame and guilt for developing cancer again were not uncommon (Ekwall et al., 2007, Griffiths et al., 2008).

It seems that some factors could have an impact on how patients experienced the news of recurrence. Mahon and Casperson (Mahon and Casperson, 1997) described how fear of recurrence became part of the daily lives of participants with thoughts of cancer returning never far away. With two exceptions (Sarenmalm et al., 2009, Step and Ray, 2011), the studies found that an awareness of the possibility of recurrence did not

lessen the emotional impact for patients (Howell et al., 2003, Mahon and Casperson, 1997, Sarenmalm et al., 2009, Step and Ray, 2011). As one participant said: *“I knew all along it could come back but let me tell you, nothing could ever prepare you for it”* (Mahon and Casperson, 1997 p.183). For some, having symptoms facilitated detection of the recurrence (Coward and Wilkie, 2000, Ekwall et al., 2007, Elit et al., 2010, Maher and De Vries, 2011, Sarenmalm et al., 2009) while others initially attributed the symptoms to non-cancer causes (Coward and Wilkie, 2000, Howell et al., 2003, Mahon and Casperson, 1997). In contrast, not experiencing any symptoms and being diagnosed on the basis of a change in a tumour marker was particularly shocking for patients (Ekwall et al., 2007, Howell et al., 2003).

2.3.2 Experiencing otherness

Recurrence of cancer had wide-ranging social impacts and challenged existing relationships between patients and those close to them. These challenges related to expression of feelings as well as managing changing bodies. Growing closer and sharing the burden of cancer was also part of the experience for some patients.

2.3.2.1 Experiencing difficulties in sharing the uncomfortable with people

Sharing emotional as well as physical suffering with family members was found to be challenging (Coward and Wilkie, 2000, Ekwall et al., 2007, Maher and De Vries, 2011). Negotiating disclosure of the diagnosis as well as receiving support in making decisions regarding treatment were also described as difficult (Maher and De Vries, 2011, Misra et al., 2013, Vilhauer, 2008). Inability to express feelings, and concerns about triggering negative reactions in people made some patients withdraw from work or leisure activities and made the experience for some a lonely one (Ekwall et al., 2014, Sarenmalm et al., 2009, Vilhauer, 2008). A feeling of becoming a burden and contributing to the family's suffering also hindered sharing the distress (Sarenmalm et al., 2009, Vilhauer, 2008, Chunlestsukul et al., 2008a).

Sharing feelings and preparations related to mortality and death was particularly challenging (Chunlestsukul et al., 2008a, Vilhauer, 2008). Chunlestsukul and colleagues (Chunlestsukul et al., 2008a) and Vilhauer

(Vilhauer, 2008) described a number of difficulties women with breast cancer recurrence experienced when trying to discuss their mortality including feeling silenced, generating superstitious fears about bringing on death and making people feel uncomfortable. Some patients also felt that by discussing death, they may be perceived as having lost their “fighting spirit” (Chunlestskul et al., 2008b, Vilhauer, 2008). The difficulties in discussing mortality were also felt in relation to clinicians (Chunlestskul et al., 2008b). However, patients valued the opportunity to discuss their death-related concerns with counsellors and support groups (Chunlestskul et al., 2008a). At the same time, maintaining normality and not being treated as an ill person all the time was also welcome by some participants (Maher and De Vries, 2011, Vilhauer, 2008). The balance between being able to talk about the experience and trying to live a normal life was difficult to achieve as families could sometimes be overprotective (Maher and De Vries, 2011, Vilhauer, 2008).

2.3.2.2 Managing their social lives with a changing body

Feelings of otherness were also generated by bodily changes as a result of treatment. A loss of physical ability and ongoing symptoms caused some to reduce their daily activity and had an impact on their quality of life (Coward and Wilkie, 2000, Ekwall et al., 2007, Griffiths et al., 2008, Maher and De Vries, 2011, Vilhauer, 2008). Accepting these physical limitations was often difficult, as it meant increased dependency on other people and losing previous roles, though support from family facilitated adjustment to these changes (Maher and De Vries, 2011). For some patients with oral cancer, the consequences of the treatment also meant an inability to communicate, which made them feel isolated (Dooks et al., 2012). Becoming frustrated with pain could also negatively impact on family dynamics (Coward and Wilkie, 2000).

An altered body image caused distress and affected individuals’ well-being and their relationships with people. Side effects and changes to bodies following breast cancer treatment were perceived as disfiguring and difficult to accept (Ekwall et al., 2007, Sarenmalm et al., 2009, Vilhauer, 2008). Some felt that their altered bodies were a visible sign of dying or otherness and as such, this triggered uncomfortable reactions from people (Coward and Wilkie, 2000, Ekwall et al., 2014, Sarenmalm et al., 2009, Vilhauer,

2008). These changes led some people to withdraw from social activities (Vilhauer, 2008), while some needed time to adjust to bodily changes before returning to their previous social lives (Dooks et al., 2012). Those in intimate relationships experienced changes to their sexual life (Ekwall et al., 2007, Vivar et al., 2009) while those wanting to form relationships perceived changes to their bodies as a barrier (Vilhauer, 2008).

A diagnosis of recurrence also seemed to create a number of changes to the daily rhythms of participants' lives, which had to be negotiated within the context of their social relationships. Fluctuating periods of deterioration and recovery were not always followed by families, which created problems (Ekwall et al., 2014). The need for support also depended on the illness cycle, which other people sometimes found difficult to understand (Vilhauer, 2008). Relentless treatment regimes meant the loss of capable bodies and demanded constant adjustment. This often resulted in careful monitoring of their bodies and sensitivity to changes (Ekwall et al., 2014).

2.3.2.3 Connecting and growing with people

For some, a recurrence of cancer resulted in positive changes to relationships. Being able to share death-related concerns was appreciated and facilitated growth and feelings of closeness with families and other cancer patients (Chunlestkul et al., 2008a, Chunlestkul et al., 2008b). Facing one's mortality and an awareness of the fragility of life could also contribute to a greater appreciation of family and friends (Ekwall et al., 2007, Griffiths et al., 2008, McCahill and Hamel-Bissell, 2009). Social and practical support from family as well as other cancer patients lessened the distress, gave them strength to carry on (Dooks et al., 2012, Elit et al., 2010) and helped in accepting and living with the limitations of the illness (Dooks et al., 2012, Elit et al., 2010, Maher and De Vries, 2011, McCahill and Hamel-Bissell, 2009).

2.3.3 Seeking support in the health care system

Interaction with health care professionals when re-entering the system following the news of recurrence was an important part of patients' experience. *Seeking and negotiating medical information and Wanting to be known and valued by clinicians* were important components of that interaction.

2.3.3.1 Seeking and negotiating medical information

Information provision and communication were integral to patients' experience of recurrence. Dealing with information about prognosis was a complex process carefully negotiated between patients and clinicians. Both patients and clinicians searched for clues on how to talk about prognosis (Step and Ray, 2011). This was well described by the authors as the "prognosis dance", as illustrated by the following participant: "*She wanted to tell me as little as possible to get me through to the next step and I pushed a bit*" (Step and Ray, 2011 p.54). The amount of information wanted and needed by patients varied. Some wanted greater recurrence-specific information, including prognosis, treatment options, reasons for recurrence and risks of further recurrences (Ekwall et al., 2007, Ekwall et al., 2011, Misra et al., 2013, Step and Ray, 2011) and carefully sought the required information (Step and Ray, 2011), while others found this level of information overwhelming (Elit et al., 2010, Maher and De Vries, 2011). Information provision could lessen anxiety and facilitate understanding of the situation. Although the clinical team was seen as the main source of information, some also wanted, but did not always get, access to other cancer patients with a recurrence to share information and experiences (Elit et al., 2010, Misra et al., 2013). Some participants also described the need to be more proactive in order to obtain the information they wanted regarding treatment and prognosis (Howell et al., 2003). Terminology related to cancer recurrence was also found to be confusing for patients, especially when compared with information provided at the initial diagnosis. This often left them needing to interpret things on their own (Step and Ray, 2011). In contrast, two studies described how information at the initial diagnosis facilitated their understanding of the situation at times of recurrence (Elit et al., 2010, Mahon and Casperson, 1997).

2.3.3.2 Wanting to be known and valued by clinicians

The nature of the relationship was also found to be an important factor contributing to either positive or negative experiences of health care at the time of recurrence. Having information provided in an approachable and sensitive way, being listened to and being offered help were facilitators of positive experiences of care (Ekwall et al., 2011, Maher and De Vries, 2011, McCahill and Hamel-Bissell, 2009). Being seen as a partner to a health care professional and sharing responsibility of care with them was

also seen as important (Ekwall et al., 2011). Continuity of care was valued as it facilitated not only the diagnosis but also more effective and trusting relationships (Elit et al., 2010). Conversely, feelings of being rushed, insensitive communication, use of jargon, lack of communication between staff and broken promises were inhibitors of positive experiences of care (Ekwall et al., 2011, Griffiths et al., 2008, McCahill and Hamel-Bissell, 2009). In a study of ovarian cancer recurrence, Howell and colleagues found that patients often perceived that clinicians' attitudes had changed and felt that they had given up on them (Howell et al., 2003). On the other hand, patients valued receiving help in making sense of the information.

2.3.4 Adjusting to a new prognosis and uncertain future

The diagnosis of recurrence often required patients to become familiar with a new disease and its implications. Previous experiences of cancer also had an impact on how the current experience was understood (Mahon and Casperson, 1997). The diagnosis of a recurrence often brought a realisation that a cure may no longer be possible and that death was now a real possibility. This was often in contrast to how they viewed their prognosis after initial diagnosis, which was more positive (Elit et al., 2010, Sarenmalm et al., 2009). Equally, having experience of a previous recurrence reinforced for some the belief that remission was once more possible (Mahon and Casperson, 1997).

Worry about further disease progression was also common (Dooks et al., 2012, McCahill and Hamel-Bissell, 2009, Vilhauer, 2008) and participants often balanced awareness of the possibility of death with hope for more time. Progression of disease usually signified fewer treatment options and transition from cure to controlling active disease or symptoms (Elit et al., 2010, Howell et al., 2003, McCahill and Hamel-Bissell, 2009, Step and Ray, 2011). As a participant with ovarian cancer recurrence noted: *"I didn't feel that I had any options, because she presented two things to me and they were dependant on the state on my health"* (Elit et al., 2010 p.321). For those who were able to have surgery, it was perceived as a better option than systemic therapy (Dooks et al., 2012, Mahon and Casperson, 1997, McCahill and Hamel-Bissell, 2009), regardless of the lack of guarantees for cure (McCahill and Hamel-Bissell, 2009). Although longing for a break, patients continued with treatment in the hope of prolonging their lives

(Ekwall et al., 2014, Maher and De Vries, 2011). The uncertainty around prognosis and changing treatment regimes was often overwhelming for patients (Ekwall et al., 2011) and prevented them from having long-term plans, which they found difficult.

2.3.5 Finding strategies to deal with recurrence

2.3.5.1 Attempting to regain control over cancer

In the context of uncertainty, attempting to take control of cancer was important for patients. Taking responsibility for one's own health by eating well or exercising was perceived as facilitating recovery following treatment and maximising the chances of survival (Ekwall et al., 2007). Adopting a fighting spirit and positive attitude were also seen as ways to aid recovery and halt disease progression (Ekwall et al., 2007, Maher and De Vries, 2011, McCahill and Hamel-Bissell, 2009). Not adhering to medication, seeking second opinions, and asking for a specific treatment or alternative therapies was an important part of this process (Coward and Wilkie, 2000, Ekwall et al., 2011, Howell et al., 2003).

2.3.5.2 Taking steps to preserve emotional well-being

Taking steps to preserve emotional well-being in the context of the threat of death was an important way of dealing with the impact of cancer recurrence. Facing one's mortality was challenging and required activities which restored emotional balance (Chunlestskul et al., 2008b). Leaving a legacy in the form of life projects was one way of lessening the impact of impending death (Chunlestskul et al., 2008a). Giving up activities which were found to evoke stress, such as employment, was taken as a conscious decision by some, and aided the preservation of emotional resources (Ekwall et al., 2014, Vilhauer, 2008). Conversely, for some, being able to maintain pre-cancer routines could help create feelings of normality (McCahill and Hamel-Bissell, 2009). Focusing on the present, taking one day at a time and accepting losses also helped participants to deal with challenges and regain wellness (Sarenmalm et al., 2009). Building relationships with people and connections with nature was found useful for some patients (Ekwall et al., 2014).

2.3.6 Facing mortality

2.3.6.1 Having to face one's mortality

Hearing news of recurrence brought to the forefront thoughts of one's mortality. Facing death and making preparations was acknowledged as emotionally challenging and required time to work through (Chunlestskul et al., 2008b, Chunlestskul et al., 2008a). Participants faced the paradox of wanting to know the implications of the diagnosis, while also preferring information to be given gradually in order to prepare to face their mortality (Step and Ray, 2011). Undertaking practical preparations and relinquishing roles was also part of this process (Chunlestskul et al., 2008a) with some realisation that this process is never complete (Chunlestskul et al., 2008b). Patients grieved for both the loss of the envisaged future and early death (Mahon and Casperson, 1997, Sarenmalm et al., 2009, Vilhauer, 2008). Experiencing symptoms triggered thoughts of death, while periods of recovery heightened the desire for prolonged life (Chunlestskul et al., 2008b).

2.3.6.2 Changing perspectives on life as a result of facing mortality

The diagnosis of recurrence provided an opportunity to evaluate previous life choices and, for a number of participants, led to a change in priorities (Griffiths et al., 2008, Mahon and Casperson, 1997, Misra et al., 2013), where previous concerns lost their importance (Griffiths et al., 2008). A heightened appreciation of life and their remaining time was common among participants (Chunlestskul et al., 2008b, Chunlestskul et al., 2008a, Ekwall et al., 2014, Mahon and Casperson, 1997, Sarenmalm et al., 2009, Vilhauer, 2008). Engaging with their mortality enhanced self-awareness of both personal strengths as well as weaknesses (Sarenmalm et al., 2009). Facing one's mortality and finalising preparations for death allowed some to live in the present (Chunlestskul et al., 2008a).

2.4 Summary of the evidence and its limitations

This meta-ethnography has demonstrated the complexity of the issues patients face when diagnosed with a recurrence of cancer. Six concepts were developed to capture these experiences: *Experiencing emotional turmoil after diagnosis*, which described the emotional impact of diagnosis; *Experiencing otherness*, encompassing changed relationships; *Seeking support in the health care system*, describing the extent of information

needs and the importance of the relationship with health care professionals; *Adjusting to a new prognosis and uncertain future*, highlighting the changes associated with uncertainty; *Finding strategies to deal with recurrence*, describing ways of maintaining emotional well-being and regaining a sense of control over cancer; and *Facing mortality*, describing the difficulties in facing death-related concerns and associated consequences.

While this meta-ethnography has highlighted the main issues experienced by patients at the time of recurrence, it also identified a number of limitations of the current research evidence.

- Firstly, the majority of studies in our review focused on breast and ovarian cancer. Only one study was identified which explored the experiences of patients with colorectal cancer recurrence (McCahill & Hamemel- Bissell, 2009). This study included only patients who were offered surgery following liver metastasis, and as such provides a limited insight into the experience of colorectal cancer recurrence. As highlighted in chapter 1, patients with bowel cancer may suffer from a number of problems not shared by other cancer patients, such as unpredictable bowel movements or having a stoma. Given the high incidence and recurrence rates for colorectal cancer, it is important to explore the experiences of this group of patients at the time of recurrence.
- Secondly, this review also highlighted the diversity of time frames used in the studies that were included. Only 6 studies explored the experiences of patients in the first year, while some were based on largely retrospective data gathered up to 6 years following news of the recurrence. Finally, some did not report how long patients had been living with a diagnosis of cancer recurrence. The time between the initial diagnosis and the recurrence of cancer also varied widely, which may also have affected their experience of the recurrence of their cancer (Vivar et al., 2009). It is important to explore patient's experiences in the first year to be able to identify key challenges at this stage.
- Finally, no studies included in this meta-ethnography were longitudinal. It is likely that the experiences and needs of patients

evolve over time and therefore it is important to study them over time. Longitudinal designs allow us to describe patients' illness trajectories in more detail and benefit from greater rapport with participants (Cunningham and Lindsey, 2007).

Chapter 3: Caregivers' experience of cancer recurrence: a literature review

3.1 Overview of the chapter

As highlighted in chapter 1, partners of patients with colorectal cancer experience a number of issues including dealing with the patient's physical symptoms, problems with stoma and uncertainty about the future. While some issues experienced by partners following the initial diagnosis of colorectal cancer may also be applicable to the stage of recurrence, some argue that recurrence is an important transition point, at which some of these issues could be either magnified or just different (Northouse et al., 2012).

In this chapter I present a review of the literature regarding the psychosocial impact of cancer recurrence on caregivers. There is a considerable lack of qualitative studies exploring the experiences of not only partners but broadly speaking caregivers at the time of recurrence. As a result, it was not possible to conduct a meta-ethnography and synthesise the literature in the same way in which patients' experience of recurrence was done. There are slightly more quantitative studies, which have focused on the psychosocial impact of recurrence on caregivers. These explore caregivers' levels of distress, factors predicting their adjustment, and issues related to recurrence, thus highlighting the key challenges that caregivers face at this time. Therefore, this review focuses on both qualitative and quantitative literature in relation to the impact of recurrence on partners of patients with recurrence of cancer. Given the paucity of both qualitative and quantitative studies exploring the experiences of partners when cancer comes back, this review includes a broad definition of partner, including caregivers or family member.

I will discuss the key challenges that caregivers face including the emotional impact of recurrence, difficulties discussing the diagnosis with patients, uncertainty of the future, caregiver burden as well as information and supportive care needs.

3.2 Literature search

A literature search was carried out in three electronic databases: Medline, CINAHL and PsycINFO. The search terms used to identify relevant articles are listed in Table 3.2. Articles published up to 2014 were included, with the search last updated in September 2014. References of relevant papers

and reviews which were identified through this search were included when appropriate.

Table 3.2 Search terms

Terms	
1	adjustment.mp
2	perception.mp.
3	"information need*".mp.
4	"supportive need*".mp.
5	"supportive care*".mp.
6	experience*.mp.
7	psycho-social.mp.
8	psychosocial.mp.
9	psycholog*.mp.
10	social.mp.
11	adaptation.mp.
12	information*.mp.
13	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12
14	(cancer* or carcinoma* or malignan* or tumour or tumor or neoplasm*).mp.
15	(secondar* or recur* or relapse* or metasta* or advanced).mp.
16	14 and 15
17	couple*.mp.
18	husband*.mp.
19	wife.mp.
20	wives.mp.
21	dyad.mp.
22	girlfriend*.mp.
23	boyfriend*.mp.
24	cohabitee.mp.
25	marital.mp.
26	married.mp.
27	famil*.mp.
28	partner*.mp.
29	spouse*.mp.
30	"sexual partner*".mp.
31	marriage.mp.
32	relative*.mp.
33	carer*.mp.
34	caregiver*.mp.

3.3 Caregivers and recurrence

The impact of cancer recurrence on caregivers has received much less attention than other stages of the cancer journey (Chekryn, 1984, Sales, 1992). To date, only two reviews have been conducted exploring the current evidence on the psycho-social impact of cancer recurrence on family members. Foy and Rose (2001) conducted a narrative literature review of studies exploring the experiences of male partners of patients with breast cancer (with both primary and secondary diagnoses). Based on seven studies identified between 1984 and 1996 which focused on recurrence, they provided a brief overview of the main issues faced by partners of patients with recurrent breast cancer including loss of hope, increased uncertainty, demands on partners, and the possible impact of these demands on distress levels (Foy, 2001). Also, Vivar et al. (2009) published a narrative review on the issues faced by patients and partners in the survivorship phase and at the time of recurrence. They also identified only eight studies during the period 1980-2007 which explored the experiences and needs of family members at the time of recurrence using qualitative or quantitative methods. They too highlighted the uncertainty and hope for further remissions as the core concerns for family members. However, the issues faced by family members were not explored separately to those of patients. Northouse et al. (2012) also provided a commentary on the issues related to each phase of the cancer journey as experienced by both patients and caregivers. While some of the concerns experienced at the recurrence stage, such as the patient's higher symptom distress and its impact on their caregiver, were also experienced at the end of life/advanced disease stage, the recurrence phase was particularly characterised as generating huge uncertainty regarding the future, as well as feelings of hopelessness and emotional turmoil.

3.4 Emotional impact of recurrence: nature and severity of distress

Several previous studies have reported the emotional impact of a diagnosis of recurrence on family members. Vivar et al. (2010) reported that family members of patients with a range of recurrent cancers perceived the diagnosis as reminding them of previous suffering, and challenging the limits of their emotional resources. Studies also described feelings of anger, shock, frustration and disappointment after learning that the cancer had come back (Chekryn, 1984, Vivar et al., 2010). The emotional impact of

recurrence seemed to be related to diminishing hope (Vivar et al., 2010) and, related to that, the increasing demands of treatment regimens (Halliburton, 1992). Partners have also been found to describe feelings of loss of control (Lewis and Deal, 1995). This was often related to feeling unable to help their loved ones (patients), or more existential concerns such as questioning their expectations about the course of life (Lewis and Deal, 1995).

In addition, quantitative studies assessing levels of distress in caregivers in cancer care have focused on the question whether caregivers experience cancer recurrence as more difficult than the initial diagnosis. This is parallel to the questions asked in research on patients. Studies have found that levels of distress in caregivers are high, with 10-30% showing signs of severe distress with these levels increasing to 30-50% when the disease is progressing. Wright and Dyck (1984) compared the level of need reported by family members following the initial diagnosis, at recurrence and in terminal stages, and found that the next-of-kin of patients with a cancer recurrence reported the highest level of needs when compared with the other two groups. However, some have argued that recurrence is no more stressful for partners than the initial diagnosis, as they have had time to adjust to changes over the course of the cancer (Schumacher et al., 1993). There may be some protective factors, such as familiarity with the system, which decrease the impact at the time of recurrence. In contrast to these studies, Gregorio et al. (2012) found that cancer-specific stress was high among spouses of patients with a recurrent cancer and in the small sample of partners of patients with cancer-free status who were experiencing ongoing physical symptoms, which may suggest that the physical demands of illness may be a better predictor of distress than the stage of illness.

Quantitative studies have also tried to determine factors predicting adjustment and distress among partners of patients with cancer. Northouse et al. (1995) found that the partners of patients receiving treatment for cancer were more distressed when compared to partners of patients who were not undergoing treatment and suffering from distressing symptoms, and found it more difficult to carry out their caring roles. Butler et al. (2005) also found that the partners' levels of distress at the time of recurrence were related to the perceived impact of the potential loss of the patient.

Some studies also found that satisfaction with care may also be an important factor in adjustment (Northouse et al., 2002), as caregivers who were less satisfied with care also had poorer mental health (Morishita and Kamibeppu, 2014).

Finally, the quantitative studies have also tried to assess whether the emotions experienced by partners are related to the emotions experienced by the patient. While it is recognised that a diagnosis of cancer also affects partners, there is mixed evidence as to whether the distress of patients is related to the distress of partners. Northouse et al. (1995) reported that patients' and partners' adjustment scores measured by Psychosocial Adjustment to Illness Scale (Derogatis, 1986) were related, suggesting that patients and carers had a mutual impact on each other. They also found that while partners' level of distress predicted patients' levels of distress, patients' levels of distress did not predict partners' levels of distress. Interestingly, husbands were significantly affected by the symptom burden, which may suggest that it is physical suffering that has the greater impact on male partners. Northouse et al (1995) has argued that women's sensitivity to emotional cues can account for these differences. They built on these findings in relation to quality of life as well and found that there was little relationship between patients' and partners' quality of. Butler et al. (2005) assessed intrusion and avoidance in a sample of patients with recurrent breast cancer and their partners and found that partners' levels of intrusion and avoidance were not related to patients (Butler et al., 2005). While the limited number of studies at the time of recurrence seems to provide mixed evidence, it is important to highlight that these studies measured different variables such as distress adjustment or avoidance, thus making comparison between them difficult.

3.5 Discussing the impact of diagnosis

Couples and family members can experience difficulties in sharing feelings with one another following a diagnosis of recurrence. Lewis and Deal (1995) interviewed couples together when the patient had recurrent breast cancer and described how patients and partners avoided certain topics. While couples seemed comfortable talking about physical aspects of illness such as treatment, discussions about the emotional impact of diagnosis were sometimes limited. Although partners initiated discussions about how women felt, these were often related to physical well-being, with only few

partners distinguishing between emotional and physical concerns. Partners also felt that women found them unsupportive when discussing their feelings. They also described talking about the patient's mortality and a threat of death as the most difficult topic. Similar findings were reported in a study by Chekryn (1984) with patients with breast and gynaecological recurrences where the diagnosis brought to the forefront issues related to mortality, which partners struggled to communicate about. Those who felt ready to discuss these feelings also described the benefits of doing so (Chekryn, 1984). As pointed out by Chekryn (1984), there is a distinction between talking about recurrence and discussing the feelings related to that diagnosis, with some patients struggling to engage with the latter. Some studies also highlighted that partners struggled with their emotions but chose not to display them in front of patients (Wilson and Morse, 1991).

3.6 Uncertainty about the future

The diagnosis of recurrence is often found to generate huge uncertainty for patients, as it challenges patients' hopes that cancer can be cured and emphasises the life-threatening nature of the illness (Mahon and Casperson, 1997, Sarenmaln et al., 2009). In quantitative studies, caregivers have also been found to report high levels of uncertainty at the time of recurrence, and sometimes even higher levels than the patients (Northouse et al., 2002). In a study of family members of patients with recurrent breast cancer it was found that family members who reported lower levels of hopelessness and less uncertainty were also less distressed (Northouse et al., 1995). In a qualitative study, partners of patients with advanced colorectal cancer also described the inability to have both short- and long-term plans following the diagnosis. While the difficulties in planning holidays or outings had an impact on their social life, they also had to face the possibility of death of a partner (Houldin, 2007). Chekryn (1984), who interviewed partners of women with recurrent breast or ovarian cancer, found that similarly to patients, the diagnosis of recurrence made them question the future as well as grieve possible future losses.

3.7 Caregiver burden

The burden of caregiving is one of the main consequences of a diagnosis of cancer recurrence for family carers, including partners. Patients with advanced cancer often receive treatment for long periods of time, which in turn may have an impact on their partner's day to-day life (Wadhwa et al.,

2013). A study involving family members of patients with recurrent cancer found that demanding treatment regimens were especially challenging if family members were required to provide care for long periods of time (Vivar et al., 2010). Caregiving can be perceived by a partner as more demanding at the time of advanced disease in comparison to the initial stage of cancer, and also posing some restrictions on their activities (Given and Given 1992). Caregivers often report struggling to find time for themselves (Gotay, 1984) and their social life (Chekryn, 1984). Carers of patients with advanced colorectal cancer, the majority of whom were spouses, also described the impact that cancer had on their day-to-day life, especially the increase in responsibilities and their struggles to manage their personal and work-related issues (Houldin, 2007). Employment seemed to be one of the main areas of difficulty for partners. These include the challenges of attending to the patients' needs or their own needs while also working full-time, and financial hardship as a result of the diagnosis (Chekryn, 1984). Wadhwa *et al.* (2013) found that in the sample of caregivers of patients with advanced cancer, 25% experienced changes to their employment status including reducing their working hours or even giving up work completely. It has been found that partners who felt supported reported fewer difficulties in their ability to carry out their caring role, and lower levels of hopelessness (Northouse et al., 1995). However, patients' physical suffering, assessed by a high symptom burden, was found to have a negative impact on carers' appraisal of caregiving (Northouse et al., 2002).

Caregiving was also found to have a negative impact on carers' health. One study found that cancer-specific stress, which was elevated in carers of patients with recurrent cancer, also compromised immune function (Gregorio et al., 2012). Qualitative studies have also reported that family members were found to neglect their own health to provide care for patients with a recurrent cancer (Vivar et al., 2010). In a qualitative study of caregivers of patients with advanced colorectal cancer it was shown that carers experienced a number of physical consequences of providing support, including difficulties with sleeping and eating (Houldin, 2007). However, it is also important to highlight that in one qualitative study, family members described positive aspects of caregiving, where providing care

seemed to facilitate closeness in the relationships and in their wider families, and counterbalance feelings of hopelessness (Vivar et al., 2010).

3.8 Information and supportive care needs

Given the uncertainty of the diagnosis of recurrence, being provided with appropriate information is important for caregivers. Studies suggest that information needs of partners are often unmet. Morse and Fife (1998), who compared the psychosocial impact of cancer at the time of initial diagnosis, following treatment and at recurrence, found that partners often reported poor communication with health care professionals especially at the time of recurrence (Morse and Fife, 1998). Other studies have also highlighted that caregivers' concerns were not listened to and they felt unable to understand the clinical aspects of the situation (Cella et al., 1990). One study exploring the experiences of caregivers to patients with advanced colorectal cancer also highlighted that they lacked information about the future implications of the diagnosis such as planning holidays or getting health insurance (Houldin, 2007).

3.9 Summary of the current literature in relation to cancer recurrence and partners

This chapter has reviewed the evidence on the impact of cancer recurrence on caregivers, including partners. Studies have highlighted the numerous challenges that caregivers may face, including the impact on their emotional well-being, physical functioning, social life and employment. While a number of reviews have called for more studies exploring the psycho-social impact of advanced cancer, including cancer recurrence, on family members (Vivar et al., 2009, Stenberg et al., 2010) this has not resulted in a substantial number of studies being published. The following section summarises the limitations of the current evidence in more detail. On one hand, it draws on the literature in relation to colorectal cancer summarised in Chapter 1, and on the other hand, the literature presented in this chapter, in relation to cancer recurrence.

- Most studies exploring the experience of partners, which focus on the stage of recurrence, were conducted at least two decades ago. The limitations of this are at least two-fold. It has been found in relation to patients' experience that those who had been diagnosed in the 1980s had a different experience of the health care

system and consequently recurrence (Mahon and Casperson, 1997). Also, the current emphasis on quality and rigour in qualitative research highlights the limitations of studies published at that time, which were of a rather descriptive nature.

- Both qualitative and quantitative evidence at the time of recurrence is limited, as the majority of studies included a widely defined group of informal caregivers including partners, children and even neighbours, and did not differentiate between the levels of distress among these different groups (Gotay, 1984, Northouse et al., 2002, Wright and Dyck, 1984). However, as argued by Foy and Rose (2001), partners are often the most involved in caring for patients and it is important to explore the issues that they face.
- The majority of studies exploring the psycho-social impact of cancer recurrence on carers included breast or ovarian cancers. To date, no study has specifically focused on colorectal cancer. Two studies explored the experience of caregivers of patients with a diagnosis of advanced colorectal cancer at the time of initial diagnosis and found the impact of increasing responsibilities and becoming a caregiver as challenging (Houldin, 2007, Sjövall et al., 2011). However, it is likely that the psycho-social challenges faced by caregivers at this stage may be different to caregivers of patients with a recurrence, as previous experiences of cancer may shape their current understanding and coping strategies.
- Finally, similarly to evidence in relation to patients' experience, a number of reviews (Li, Mak & Loke, 2013, Stenberg et al., 2010) have highlighted the need for longitudinal studies to allow the exploration of the evolving experiences of family members, including partners, as a key research priority.

3.10 Aims of the current study:

Gaining a better understanding of patients' and partners' experience is vital, as this will allow us to design appropriate interventions to reduce patients' and partners' emotional burden. This study will attempt to explore the experiences of patients with a recurrence of colorectal cancer and partners

of patients, with a view to providing the understanding needed to inform best possible care for patients and partners.

The overarching research questions are as follows:

- How do patients and partners of patients experience a diagnosis of colorectal cancer recurrence?
- What are the supportive needs of patients and partners of patients at the time of colorectal cancer recurrence?
- Do the experiences and needs of patients and partners of patients with a diagnosis of colorectal cancer recurrence change over time?

Chapter 4: Methodology

4.1 Overview of the chapter

As highlighted in Chapters 2 and 3, there is a lack of qualitative studies exploring the experiences of patients with a recurrence of colorectal cancer and partners of patients over time. This chapter comprises two parts. In Part I, I describe the methodology chosen to answer the research questions outlined in Chapter 3. Firstly, I introduce the methodology used, namely Interpretative Phenomenological Analysis (IPA), and the rationale behind choosing this approach. I also describe IPA in the context of longitudinal research and its application in this thesis. In part II, I describe the recruitment, data collection and analysis process for this study.

4.2 Part I- IPA methodology

4.2.1 What is IPA- theoretical underpinnings

IPA draws on three theoretical positions including idiography, phenomenology and hermeneutics.

One of the most important underpinnings of IPA is idiography, which acknowledges the value of the individual and is concerned with gaining an in-depth understanding of the particular individual, in a particular setting, at a particular time. This is in clear contrast to the nomothetic psychology which focuses on the group level. IPA has embraced the idiographic focus by conducting studies using small samples or even adopting a case study design (e.g. Bramley and Eatough, 2005, Eatough and Smith, 2006). The rationale behind the idiographic focus is that it not only brings us closer to the individual, but also to what might be the shared aspect of the experience between the individual and other people in the same situation (Smith, Flowers and Larkin, 2009).

The second theoretical tradition important to IPA is phenomenology. The phenomenological aspect focuses on gaining an understanding of what matters to the individual. IPA is influenced by work from a number of phenomenological philosophers, who were interested in studying the human experience. The key figures in phenomenology, which IPA draws upon, are Edmund Husserl, Martin Heidegger and Maurice Merleau-Ponty. In line with Husserl (Smith et al., 2009) when using IPA, we try to identify the key qualities of the given phenomena, which could in turn illuminate the

experience of others. In order to be able to do so, Husserl famously urged people to adopt a phenomenological attitude to “go back to the things themselves”. As all of us make assumptions about different experiences, “bracketing off” our assumptions should enable us to see the objects as they really are. Building on this, Merleau-Ponty and Heidegger also acknowledge the importance of the social context to the individual experience. Heidegger sees the individual as being “thrown” into a world of objects, and as part of that world, being socially, temporally and physically embedded in the world (Heidegger, 1972), while Merleau-Ponty sees our being in the world defined by our embodied experience (Merleau-Ponty, 1945).

Phenomenology goes hand in hand with a hermeneutics approach; we do not simply have access to someone’s experience and therefore we need to engage in the process of interpretation (Smith et al., 2009). Hermeneutics is interested in uncovering the meaning of the text and the process of interpretation. Gadamer and Heidegger draw our attention to the importance of the interpretation and our own assumptions when interacting with data. While Gadamer highlighted the dynamic interaction between the meaning of the text and our fore-understanding (Gadamer, 1976), Heidegger challenged the notion whether it is possible to completely bracket off our previous experiences and knowledge by arguing that we can only achieve that partially at the interpretation stage, which moved him closer to the hermeneutic phenomenology (Smith et al., 2009). In fact, one never has direct access to another’s experience and the construction of the phenomena is done by both participant and the researcher. The hermeneutic cycle has an important place in IPA, as it highlights the importance of the part to understand the whole. This can be understood on a number of levels (Smith et al., 2009): the meaning of the word in the context of the whole sentence; the meaning of the extract in the person’s account or the meaning of the event in the person’s life. This move between the part and the whole is an iterative process and facilitates the engagement with data. Hermeneutics are closely linked to the role of the researcher, in that the researcher is trying to make sense of the participant’s sense-making processes. This process, also known as the double hermeneutic, clearly highlights the importance of taking into account

the researcher's own assumptions and thought processes involved in the analysis (Smith, 2007).

4.2.2 Why IPA?

Qualitative research methodologies have experienced major changes in the last three decades, with a number of different approaches being recognised and valued (Lyons and Coyle, 2007). IPA (Smith et al., 2009) has been chosen as a methodology to explore in-depth lived experiences of patients with colorectal cancer recurrence and their partners, the meaning of these experiences and the processes involved in making sense of the diagnosis. It has been argued by some that phenomenological approaches are particularly suited to answer questions about the nature of experience (Willig, 2008). While grounded theory is also interested in how people may adjust to illness, it has its roots in sociology and focuses largely on social processes, rather than individual experiences. In contrast, IPA follows an inductive approach, which is particularly important as colorectal cancer recurrence is an unexplored area, and will provide an opportunity to explore the issues pertinent to patients and partners from their own perspective. Similarly, while the discursive approach focus on language may illuminate that people may describe their experiences in different ways (the argument often raised against phenomenological approaches), its main criticism is the rejection of subjectivity, where there is no place for internal processes (Willig, 2008). In that sense, discourse approaches are not able to answer questions regarding people's experiences but only how these are constructed by language. In contrast, IPA takes a critical realism perspective and is interested in how people experience and perceive their particular situation (Willig, 2001).

IPA is particularly well-suited to the exploration of topics that create significant changes in people's lives (Smith et al., 2009). It draws on the Dilthey's definition when thinking about what constitutes a significant experience or comprehensive unit in that it usually may challenge the flow of everyday life and may have consequences for the individual (Dilthey, 1976). It therefore lends itself to the topic such as cancer recurrence. While narrative approaches, similarly to IPA, are also interested in key events in people's biographies, the focus is on the way people tell stories rather than individual experiences.

4.2.3 Qualitative Longitudinal Design (QLD) and IPA

In this Section, I will provide an overview of QLD and describe how IPA can be used using longitudinal design.

In the simplest terms, we can talk about QLD when we collect data on at least two occasions (Ritchie, 2003). The aim of QLD is to explore changes over time with the focus on transitions of both individuals and organisations (Koro-Ljungberg and Bussing, 2013). Overall, QLD has two benefits. Firstly, it enables us to explore the evolving experiences and needs of the target sample. Secondly, it facilitates the gathering of rich data by establishing a rapport with the participant over time (Murray et al., 2009).

When combining IPA methodology and longitudinal design it is important to consider a number of issues. As described earlier, IPA draws on three theoretical positions and these should be considered in the design of any research project using IPA. Firstly, at the sampling level, an idiographic focus means that studies employing IPA as a methodology are usually small, to facilitate an in-depth analysis (Smith, Flowers & Larkin, 2009). Since the focus in IPA is the exploration of the particular significant phenomena, the samples in IPA studies are also usually homogenous. This facilitates the exploration of the similarities and differences across individuals. Secondly, at the analysis level, the idiographic approach means that one does not move onto the next case until a detailed examination of the first case is achieved. Hermeneutics along with phenomenology bring our attention to the fact that when analysing data we are not merely describing but also interpreting participants' experiences. Finally, at the writing stage, the idiographic focus means that when presenting themes at the group level one does not lose the individual experience.

It is important to consider the implications of using IPA in the context of longitudinal design. Firstly, the sample size may be even smaller to be able to maintain the idiographic focus. However, because of the potential attrition in longitudinal studies, especially in patients with deteriorating health, it cannot be too small. Secondly, at the analysis level, it means that one focuses on the change within case before exploring the similarities and differences between participants (a detailed description of this process is presented later in this Chapter). Finally, ethical issues may be amplified

when adopting a longitudinal design. In order to minimize the feeling of coercion, consent should be a continuous process throughout the study.

4.3 Part II

This Section describes the design of this study, the recruitment process, data collection and analysis.

4.3.1 Design

A qualitative longitudinal study exploring the experiences of patients and partners over time following the diagnosis of colorectal cancer recurrence.

4.3.2 Patient involvement

Service users were involved in the project to ensure its acceptability and to maximize recruitment. Firstly, an outline of the project was presented at the Thames Valley Consumer Partnership Network meeting where it was enthusiastically received. Active and advanced disease was identified by members as an important research area needing more attention. Secondly, the topic guide and all participant-related documents were read and commented on by three service users (two patients and one partner). No major changes were suggested and the topic guide was deemed as appropriate and relevant. The topic guides can be found in Appendix 2.

4.3.3 Ethics

The study gained approval from Oxford Brookes University Ethics and Committee as well as NRES Committee South Central- Oxford B (12/SC/0214). Approval from Research and Development Department for each research site has also been obtained. The approval letter from the NRES Ethics Committee can be found in Appendix 3.

4.3.4 Recruitment of patients and spouses/partners

Patients were recruited from colorectal outpatient clinics in four NHS sites: University Hospitals Birmingham NHS Foundation Trust, University Hospitals Southampton NHS Foundation Trust, Oxford University Hospitals NHS Trust and Royal Berkshire NHS Foundation Trust. Following discussion with the Clinical Nurse Specialist (CNS) in each hospital, a recruitment procedure was devised. Eligible patients were identified at the Multidisciplinary Team meeting (MDT). They were then approached by members of the clinical team (mainly CNSs) at subsequent outpatient appointments. Patients were not approached until at least the second appointment after receiving news of recurrence. Members of the clinical

team verbally explained the study and provided potential participants with an Invitation Letter (Appendix 4), Participant Information Sheet (Appendix 5) and a Reply Slip (Appendix 6). They were also provided with information about the study for their spouse/partner, if applicable and a Reply Slip for their spouse/partner. Patients were asked to provide their spouses/partners with these documents so they could consider participating in the study (See Appendix 7 for the Information Sheet for Partners).

4.3.4.1 Initial recruitment strategy

The initial strategy adopted involved asking patients who were interested in the study to indicate this on the Reply Slip enclosed with the Information Sheet and post it to the researchers in the pre-paid envelope provided. Patients interested in taking part were to be then contacted by the researcher to further explain the study. However, after a period of 5 12 weeks, this recruitment strategy did not result in the return of any reply slips. The feedback from nurses indicated that, in practice, they felt they did not have sufficient time to introduce the study to patients and they also felt that patients may have found it a burden to have to send the Reply Slip back themselves.

4.3.4.2 Revised recruitment strategy

The protocol was thus changed so that the patients could indicate on the Reply Slip whether they would be interested to hear more about the study (rather than interested in taking part) and they could then leave the Reply Slip with the nurse who forwarded it to the researcher. This was submitted as Amendment to the NHS Ethics Committee (See Appendix 3 for the Approval letters of Amendments 2 and 4). Also, whilst the aim was to introduce the study in person wherever possible, in some instances it was not deemed appropriate by the nurses to introduce the study face-to-face, and therefore a letter was sent via post instead. Therefore, some patients were also invited to the study by post and followed the same procedure of indicating interest. This was also submitted as Amendment to the NHS Ethics Committee (See Appendix 3 for the Approval Letter- Amendment 5). Then, the participants (both patients and partners) were contacted by phone to see if they had had time to read all the information, to answer any questions they may had and to see if they wanted to take part. If they were interested, an interview was arranged at a time and place convenient to the participant. At the end of the first interview, participants were asked

whether they would be happy to be contacted by the researcher in a few months' time to see if they were still interested in taking part in the second interview. Therefore, patients were not consenting to taking part in the second interview, but only indicating interest (See Appendix 8 for the Consent Form).

4.3.4.3 Social Media recruitment

As recruitment to the study using the methods described above was very slow, it was decided to extend recruitment to online communities. Firstly, a number of links were established with key stakeholders from the third sector. These included Bowel Cancer UK, Beating Bowel Cancer and Cancer Research UK. Advertisements were prepared and posted on Bowel Cancer UK Facebook page, Beating Bowel Cancer Forum, and Cancer Research UK forum and were emailed to subscribers to the mailing list of Bowel Cancer UK. Information about the study was also tweeted on a fortnightly basis. These communities are open for both patients and families and thus remove the onus from the patient to introduce the study to their partners. This was submitted as Amendment 3 to the NHS Ethics Committee (See Appendix 3 for the Approval Letter- Amendment 3).

4.3.5 Reflection on the recruitment difficulties

Given the sensitive nature of the topic, I had expected that it may be difficult to recruit into the study. However, the progress was much slower than anticipated. It seems that one of the main barriers to recruitment into this study was identifying an appropriate time for nurses to approach patients. I had ongoing discussions with nurses recruiting into the study who often commented that there was limited time at the appointment to discuss the study or that they felt uncomfortable bringing up the possible participation in the research study given the news patients had recently received. This in turn inhibited the recruitment of partners. The extent to which nurses felt comfortable in discussing patients' participation varied, with health care professionals working in the hospitals where research was more integrated with service delivery approaching more participants. Also, while it is difficult to say how many people with colorectal cancer recurrence saw the advertisement on social media, a similar number of patients and partners recruited via this method in comparison to the NHS suggests that at least some patients and partners did want to discuss their experiences. Postal invitation was a more successful method of recruitment as it

removed the potential burden of discussing the study with patients at a difficult time.

4.3.6 Sample

Initially, the aim of the study was to capture people's experiences of recurrence as close to diagnosis as possible. Although some variability in timing of the interviews was expected, the initial inclusion criteria for patients were: a) patients who were diagnosed with colorectal cancer recurrence in the last 1-2 months; b) who will be receiving active treatment e.g. surgery, chemotherapy, radiotherapy; c) not suffering from other serious illnesses; d) able to speak English and able to give consent. The inclusion criteria for partners were: a) identified by the patient as a partner; b) able to speak English and give consent.

For participants recruited via a postal invitation, the inclusion criteria in relation to the timing of diagnosis and interview changed and included patients "diagnosed recently" rather than in the previous two months.

For participants recruited via Social Media, the criteria were broadened, as it was expected that patients at different stages of recurrent disease would respond to the advertisement. Thus, the inclusion criteria for patients were: a) adult cancer survivors who have been diagnosed with a recurrence of colorectal cancer in the last year; b) able to speak English and c) able to give consent; For partners: partner to a person who was diagnosed with a recurrence of colorectal cancer in the last year; b) able to speak English, c) able to give consent.

4.3.7 Data collection

4.3.7.1 Semi-structured interviews

Participants were interviewed at two time points. All participants chose to do the interview in their homes, apart from one who chose a café. The initial study design was that the first interview was to take place within 1-2 months after diagnosis and the second within 1-2 months after treatment completion. Because of the difficulties with recruitment described earlier, it was not possible to talk to participants soon after the diagnosis of the recurrence. Therefore, in practice, the first interview with patients and partners was conducted within 4-12 months of the patient's diagnosis of recurrence, with the second interview 4-7 months later. Interviews were

semi-structured to ensure balance between flexibility and consistency (Smith et al., 2009) and followed a topic guide. While the topic guide allowed for an exploration of issues relevant to the research question consistently to a large extent across the whole sample, there was a flexibility, which allowed taking the conversation where the participant wanted it. The first interview aimed to capture the reaction to the news and participants were encouraged to tell their story as a patient/partner from the time of initial diagnosis. It was felt important to give participants an opportunity to recount their story from the beginning. It also helped participants by providing the framework to describe events chronologically and also enabled the participant to be in charge of the interview and be an informant. The second interview was designed to explore further changes in participants' lives, for example treatment regimes. However, in addition to their responses to these key events, I was interested in changes in the participant's meaning-making processes and differences in the significance attributed to events in response to the passage of time. The second interviews started with the general question: "can you please tell me what has been happening in your life since I last saw you". There were also a number of areas explored at both time points such as the impact of illness on day to day living, coping strategies, relationship with the clinical team and the supportive and information care needs throughout their illness trajectory. All interviews were audio-recorded and transcribed verbatim. The average length of the interview was 62 minutes, ranging from 40- 80 minutes. Following the interview, participants completed brief demographic form (Appendix 9).

4.3.7.2 Patient / partner interviews

The aim of this study was to gain an insight into the impact of colorectal cancer recurrence from two perspectives, patients and partners, with the focus on experiences of patients and partners as two separate groups rather than their experiences as couples. Therefore, the interviews were conducted separately with patients and partners; however they took place on the same day. The same process followed at the stage of analysis: patients' and partners' interviews were analysed in their own entity rather than together. While partners are one of the main sources of support for patients, it is important that we explore their experiences in their own right. This allows us to identify the needs and concerns relevant to patients and

partners respectively. Furthermore, joint interviews, often used in studies focusing on couples may be also unsuitable for sensitive topics (Seymour et al., 1995, Valentine, 1999).

4.3.7.3 Reflexivity

Following each interview, I wrote a research journal to record any observations about how the interview went, the context of the interview and any feelings it generated for me. This was used later as part of the analysis process. While the aim of having another person looking at data from interviews in qualitative studies is not to provide exactly the same interpretation, it is also important to examine the process of analysis according to criteria set for qualitative research. Henwood and Pidgeon (1992) suggest the importance of fit, as one of the criteria against which we should evaluate the rigor in the research process. It refers to the extent to which codes and themes generated by researcher fit data (Henwood and Pidgeon, 1992). This was particularly discussed in the ongoing meetings with my supervisors. The credibility rather than reliability of the analysis was the aim of discussing the analysis with supervisors as well as colleagues from the cancer care research group (Elliott et al., 1999).

4.3.8 Analysis

In this section I present the approach used to analyse the interview transcripts of patients and partners. I adopted the approach of Interpretative Phenomenological Analysis and followed steps outlined by Smith et al. (2009). Because of the longitudinal aspect of this study, additional steps were introduced (Spiers, Smith & Drage, 2015). The first stage of the analysis focused on analysis within case. Firstly, each interview was analyzed independently in its own right to explore the experiences at that particular point. Secondly, analyses at time 1 and time 2 were then brought together to compare similarities and differences in order to explore temporal change and continuity in that experience.

For analyzing both time 1 and time 2 for all of the interviews, I took the following steps. Firstly, I read each transcript several times to familiarize myself with the data. Then, I wrote my initial thoughts on the right hand side of the transcript, which focused on three components: descriptive, linguistic and conceptual (Smith et al., 2009). Descriptive comments aimed to describe what was happening for the participant (for example giving up

work) linguistic comments highlighted interesting or unusual use of language including metaphors (e.g. cancer recurrence as prison or death sentence) and conceptual comments involved an initial attempt at interpretation with close attention to participants' words (reaching limits of his suffering).

I then moved to the left hand side of transcript and used these initial notes to form themes. The creation of themes was focused on balancing the experiential components as well as interpretation. I then transferred each theme onto post-it notes alongside the key words which represented that theme. Some themes were also divided into sub-themes to allow more in-depth analysis. I then grouped the themes to create the superordinate themes with the aim of moving the analysis to the conceptual level without losing the detail. This was especially important as the data were to be analysed longitudinally as well. Finally, I produced a table of themes for each participant for each interview.

Once the table of themes for time 1 and time 2 were completed for a particular participant, they were compared to each other. The comparison process was conducted initially at the level of superordinate themes and later at the level of themes with the focus on the potential differences and similarities in their experiences both on clinical as well as psychological levels. Clinical changes could refer to changes in treatment or prognosis and psychological changes could refer to changes in adjustment, meaning-making and understanding of the situation. This process was iterative and some themes were moved around to create a coherent story of the participant's experiences. Given the amount of data, some of the themes had to be discarded at this stage. As a result, a final master table of themes was created for each participant, consisting of a superordinate theme and themes. A superordinate theme for both time points was then created: a longitudinal superordinate theme. For example: for Kate, a superordinate theme at time one: *Recurrence-triggered transformations of self, causing family difficulties* and the superordinate theme at time 2: *Trying to make sense of her new needs*, contributed to the longitudinal super-ordinate theme: *Balancing new and old roles in the family context*. The process is illustrated in Figure 4.3.8a, while an example of the process is presented in Table 4.3.8.

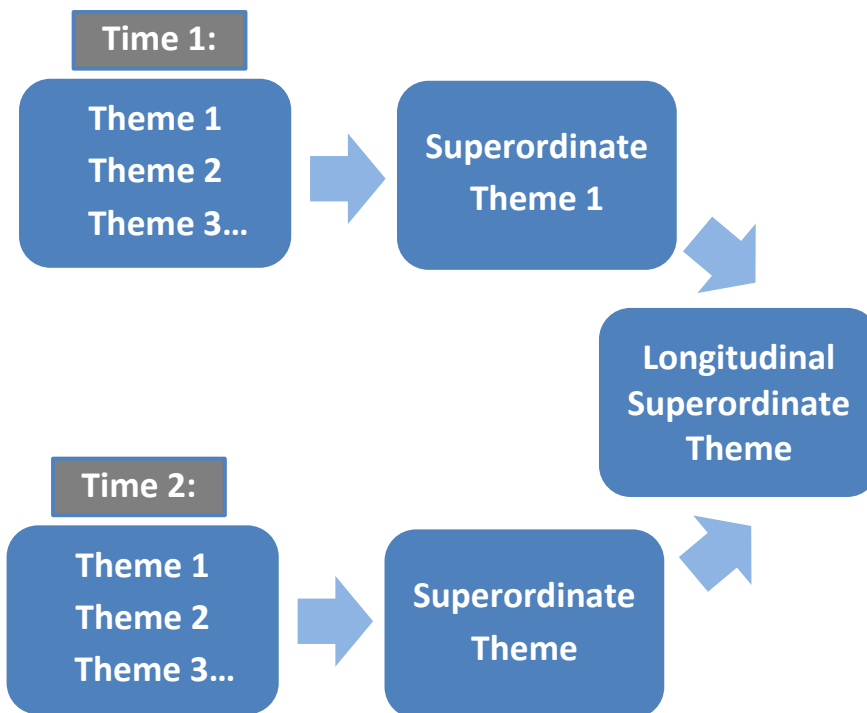


Figure 4.3.8a Illustration of the within case analysis

Table 4.3.8 Extract from one of the participant's table of themes for time 1 and 2 together with longitudinal theme.

Superordinate longitudinal theme: Balancing new and old roles in the family context	
<p>Superordinate theme time 1: Recurrence-triggered transformations of self, causing family difficulties</p>	<p>Superordinate theme time 2: Trying to make sense of her new needs</p>
<p>1. Finding safe haven in nurses <i>So all of a sudden you have got a couple of nurses , they are there to help you, who you hold on into that, cause I did not want to put everything, all of my feeling to my husband</i> <i>I don't know whether it is because of I have such a weird family. They do not show feelings [...] all of a sudden you are in the environment where they show you a lot of care and they want to look after you and make you better, it is very difficult breaking away.</i></p>	<p>1. Leaving the support from nurses behind <i>I haven't contacted her [CNS nurse] for support for a while. I think there's been times when, when I've wanted [...] a lot of hand holding to get through different times.</i></p>
<p>2. Establishing new self in family causing frictions <i>Their attitude is that they do not want me to do anything, they want to treat me with the kid gloves, wrap me in the cotton wool and</i> <i>I hit the roof. This is Kate that would, would never question anything, and I would never answer</i></p>	<p>2. Experiencing different relationships with family following diagnosis <i>Because she doesn't seem to know how to talk to me the same anymore, so she tiptoes, I sense that a lot of the way in which I am now, which is more positive and more outspoken, she doesn't like that change.</i></p>

As conducting analysis at time 1 was likely to influence the analysis at time 2, care was taken to “bracket off” the analysis at time 1 when looking at data from time 2 to allow new themes to emerge. Inevitably, this was not always possible and some similarities and differences became visible and these were noted. I focused on each interview separately and completed my analysis before moving on to the next interview.

The analysis then moved to cross case analysis. Superordinate Longitudinal themes for all participants were compared to each other and Cross Case Superordinate Longitudinal themes were created. Again, while the comparison process was conducted initially at the level of superordinate themes, later it was also conducted at the level of themes and sub-themes to ensure that theme encompassed the particular aspect of the experience for all participants. This process is illustrated in Figure 4.3.8b. For example, *Balancing new and old roles in the family context* (Superordinate Longitudinal Theme for Kate), was grouped with *Going towards death together and alone* (Superordinate Longitudinal Theme for James), and later on became part of the Cross Case Longitudinal Superordinate Theme: *Sharing and not sharing the experience of recurrence*.

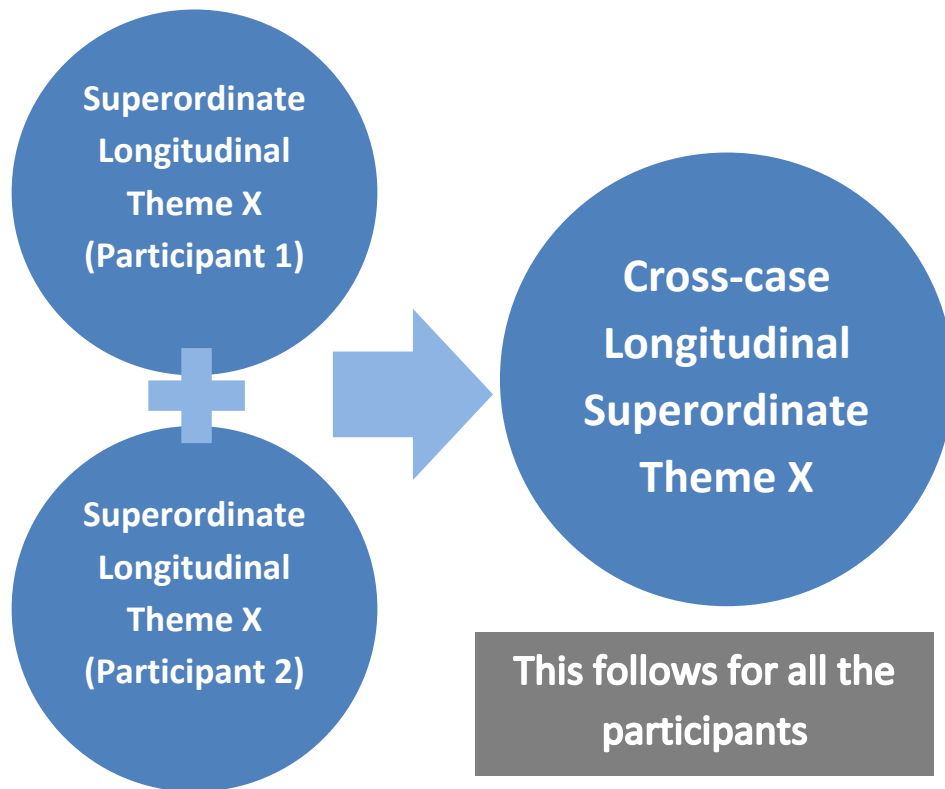


Figure 4.3.8b The process of creating Cross-Case Longitudinal Superordinate Theme

In line with the iterative nature of the analysis process, the analysis continued throughout the writing-up stage. By privileging the focus on the changes and continuity within each individual, it was possible to explore the divergence and convergence across the cases (Spiers et al., 2015).

Chapter 5: Patients' experience of colorectal cancer recurrence

5.1 Chapter overview

In Chapter 5, I present the findings from the longitudinal qualitative study on patients' experience of colorectal recurrence. I first present participants who contributed to the study. I then present Three Cross Case Longitudinal Superordinate Themes which describe patients' experience.

5.2 Participants: patients

Ten patients responded to the invitation and returned a reply Slip. Two did not meet the inclusion criteria (not offered active treatment). Thus the initial sample included eight patients (4 males and 4 females). However, one participant died before the second interview, and another was not able to be contacted. These two participants were excluded from the study. Six remaining participants were interviewed twice. Summary of patients recruited into the study is presented in Table 5.2a, and the dyads described in the study are presented in Table 5.2b.

Table 5.2a Summary of the patients recruited into the study.

Pseudonym	Sex	Age	Recruitment method	Occupation
James	Male	41	Social Media	Business Development Manager
Kate	Female	47	Social Media	Self-employed
Johanna	Female	59	Social Media	Assistant Manager in NHS
George	Male	62	NHS (face to face)	Retired from paid work
Linda	Female	65	NHS (postal)	Retired from paid work
Chris	Male	62	NHS (postal)	Owner of taxi company

Table 5.2b Dyads described in the study

Patient	Partner to
James	Victoria
Kate	Michael
Johanna	Alan
George	---
Linda	Anthony
Chris	Louise

5.3 Pen portraits of the patients

James-partner to Victoria

James was diagnosed initially when he was 40 years old. He was working as an IT Manager in the private sector. He was diagnosed in an NHS hospital but used his private insurance subsequently to pay for his treatment. Following the initial diagnosis in 2010 he underwent surgery, followed by chemotherapy. He subsequently returned to work and went back for a routine test, which revealed that his cancer had metastasised to his liver. Initially, he was told that it was not operable and was offered only chemotherapy. However, chemotherapy worked well and he was told that he was eligible for further surgery. Following surgery, he was encouraged to have chemotherapy, which he was reluctant to accept. His surgeon requested additional tests to help him make a decision, which revealed that his cancer had metastasized to his back, liver and bowel. Following the news, he started chemotherapy immediately. Since then, he had undergone a number of changes to his chemotherapy to ensure its effectiveness. He did not require a stoma.

Kate-partner to Michael

Kate was concerned about her symptoms for a long time and made numerous visits to the GP and even an emergency department at her local hospital. She was finally referred for a colonoscopy, which revealed that she had cancer in her bowel. She underwent surgery and adjuvant chemotherapy. Following that, she attended her first follow up appointment, which revealed that the cancer had metastasised to her liver. She was eligible for further surgery, which she had in December 2012. After the

initial diagnosis, she was unable to continue her work and at the time of the second interview was trying to return to work. She did not require a stoma.

Johanna- partner to Alan

Johanna had been experiencing symptoms for a year and also consulted her GP on a number of occasions who advised her that she had Irritable Bowel Syndrome. Similarly to Kate, she was finally referred for a colonoscopy, which showed that she had colorectal cancer. She attended annual follow-up appointments and, two years following the initial operation, she was told that the cancer had metastasised to her lung, bowel and liver. Consequently, she was offered chemotherapy only, which she had been on since then. After hearing about her poor prognosis following recurrence, she applied for early retirement from her NHS job and by the time of the second interview her application had been accepted. She did not require a stoma but had been suffering from incontinence since the initial operation.

George-(partner did not take part)

George had been experiencing problems with bowels since 2003. He had visited his GP on a number of occasions and, similarly to Johanna, was told that he had Irritable Bowel Syndrome. Following a rectal bleed, he went to the hospital and was referred for a colonoscopy. This showed that he had a polyp, which was not cancerous and was removed in 2009, following which he had temporary stoma. The reversal operation was carried out in June 2010. In October 2010, he started having problems with his bowel again and went back to his GP. Following tests, it was revealed that some polyp was left after the previous operation and George was diagnosed with colorectal cancer. As a result, he underwent radiotherapy and then surgery in July 2011. Following that operation, he had a stoma put in again. A year later, he was scanned again and it was found that his cancer had come back in both his lungs and pelvic region. Following that, he underwent surgery in August and October 2012. Following the operation and scan, he was told that his cancer had come back again in his lungs and pelvic region and was offered chemotherapy only.

Linda-partner to Anthony

Linda was referred by her GP for a colonoscopy relatively quickly, which showed that she had colorectal cancer. She underwent an operation to

remove the tumor. Two days later, she was rushed to the hospital and found out that some of her cancer was missed during the initial operation. Following that, she also had chemotherapy. This meant that it took her long time to recover. She had a stoma as a result of the operation. At the end of the chemotherapy cycle, she had a scan, which showed that her cancer had spread to her ovaries. She was told that she was not eligible for further surgery, however, consulted a surgeon as a private patient, who said that they may be able to help her. Subsequently, she was able to be operated on by the same surgeon as the NHS patient. She was warned that she may lose her leg as a result of the operation, but this turned out not to be the case. At the time of the first interview, she was lying in her bed as she was still recovering from the operation. Before the diagnosis, she was retired and enjoyed gardening, which she had been unable to do since the news of having cancer. By the time of the second interview, she was feeling physically strong and had returned to her previous activities, for example walking.

Chris-partner to Louise

Chris was diagnosed with colorectal cancer as a result of a routine screening programme for people over 60. He was offered surgery and had to have a stoma as a result of that for which he underwent reversal surgery a year following completion of the initial treatment. He was attending annual follow up appointments and two years after the initial surgery he was diagnosed with the recurrence of cancer in the liver, following which he was deemed eligible for further surgery. As a result of this surgery, he was unable to control his bowel movements but refused to have a stoma. At the time of the first interview, he was unable to return to work as a result of his problems with his bowels.

5.4 Findings

In this section I present three Cross Case Superordinate Longitudinal Themes: Theme 1: "*Making sense of the meaning of diagnosis*", Theme 2: "*Trying to negotiate the place of cancer in one's life*" and Theme 3: "*Sharing and not sharing the experience of recurrence*" (Figure 5.4). The remainder of this Chapter is divided in three sections with each section presenting one Cross Case Longitudinal Superordinate Theme (Part A), followed by its discussion in relation to the current literature (Part B).

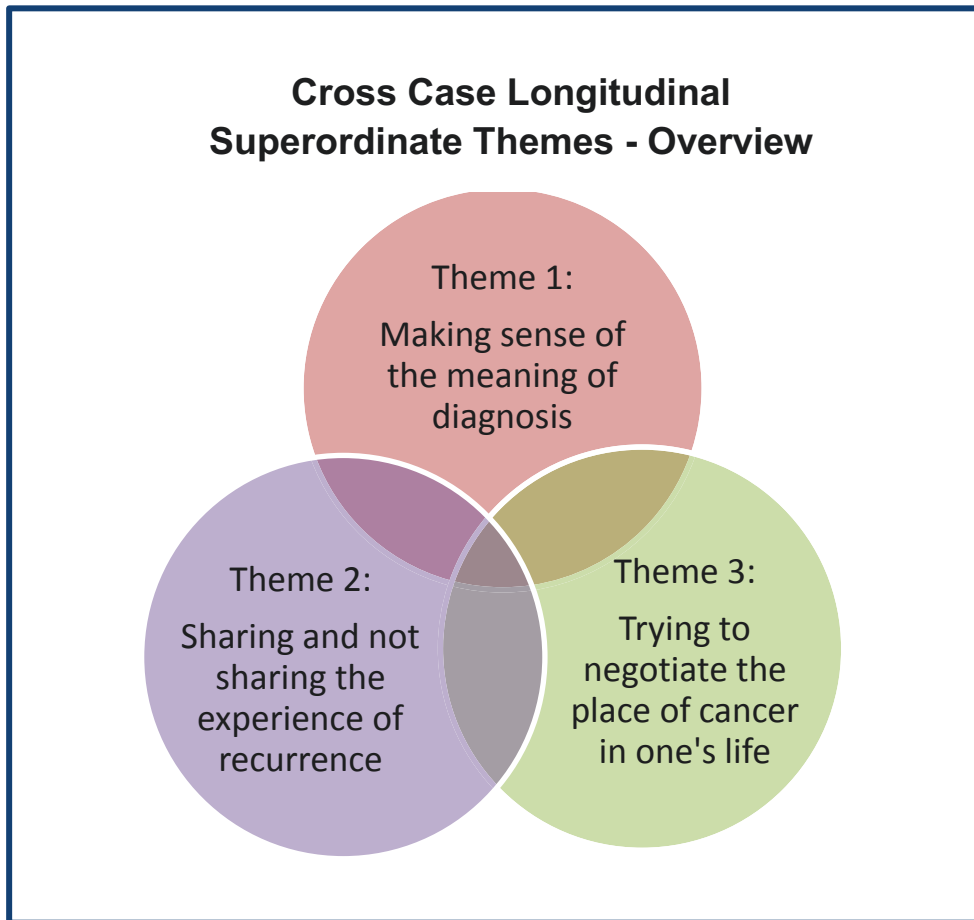


Figure 5.4 Cross Case Longitudinal Superordinate Themes – Overview

**5.4.1 Part A- Cross Case Longitudinal Superordinate Theme 1:
“*Making sense of the meaning of diagnosis*”**

The Cross Case Longitudinal Superordinate Theme 1: “Making sense of the meaning of diagnosis” describes the difficulties patients face when trying to process and understand the news of recurrence and its potential meaning. It highlights the constantly changing nature of the disease, and consequently patients’ understanding of their prognosis and the treatment available to them. It also reveals how information is negotiated between clinicians and patients and how this in turn impacts on their relationships.

The theme describes how participants initially react to the news of recurrence. This description demonstrates that a patient’s experience of the initial colorectal cancer diagnosis is an important framework for making sense of their recurrence diagnosis. A patient perception of the risk of recurrence plays an important role in determining how they react to the

news of recurrence, whilst a perception of the risk of recurrence is also determined by previous experiences such as a number of clear follow up tests which patients had, information provided following completion of the initial treatment and one's beliefs. All of these aspects of the patient's previous experience may influence how they react to the news of recurrence.

Once receiving the news, participants then try to make sense of the recurrence diagnosis. This process does not happen in isolation either but to a certain extent in the context of the patient's previous experiences. More specifically, patients use their previous experiences as a benchmark, comparing how similar their previous and current situation is. For example, offering the same type of treatment for recurrence as the participant had previously seems to facilitate the meaning making for the participants. While similarity between previous and current situations provides some reassurance, this reassurance is often not enough. In contrast, lack of familiarity in the form of being offered a different treatment mode to the one at the time of the initial diagnosis, or previous negative experiences, seems to create substantial anxiety.

Following completion of the treatment, patients face further ongoing struggles in making sense of the prognosis of their condition. The importance of familiarity of the treatment, or lack of it, seems to slowly diminish and patients focus more on the overall prognosis and the current experience of illness. While patients with poorer prognoses seem to struggle with changing treatment regimes, which could mean regaining control over cancer or disease progression, patients recovering from surgery struggle with uncertainty of the effectiveness of this treatment.

As previously described in the Methodology chapter, Table 5.4.1 sets out the Cross Case Longitudinal Superordinate Theme 1 and then, for each patient, their individual within case Longitudinal Superordinate Theme, together with their individual Superordinate Theme at Time 1 and at Time 2, and Subordinate themes identified.

Table 5.4.1 Cross Case Longitudinal Superordinate Theme 1: Making sense of the diagnosis

Cross Case Longitudinal Superordinate Theme 1: Making sense of the diagnosis		
<p>Kate: Being on alert for another threat of cancer</p> <p>Time 1: Making sense of escalating concerns becoming a reality</p> <p>At the time of the first interview, Kate's account focuses initially on the time leading to the diagnosis and her attempts to prepare herself for the news. This in turn, seems to minimise the negative impact on how she receives the news of recurrence. She tries to balance the perceived threat of the situation with the offer of surgery. Following the operation, she does not feel free of cancer, mainly because of experiencing ongoing symptoms.</p> <ul style="list-style-type: none"> ✓ <i>Preparing herself for the future problems following initial diagnosis</i> ✓ <i>Experiencing lessened emotional turmoil when being told</i> ✓ <i>Balancing the impact of recurrence with the treatments available</i> ✓ <i>Not feeling able to celebrate clear tests</i> 	<p>Chris: Cautiously celebrating the possibility of an extended future</p> <p>Time 1: Overcoming the immediate threat of death</p> <p>At the time of the first interview, Chris describes an anxious wait leading to the diagnosis and then start of the treatment. Following the operation, he tries to gain an understanding of his situation and prognosis. This is challenging though as seeking information means potentially realising the severity of the situation. He highlights the fragile nature of the first clear scan while also hoping for the future.</p> <ul style="list-style-type: none"> ✓ <i>Enduring distress leading to operation and diagnosis</i> ✓ <i>Trying to make sense of the meaning of the diagnosis</i> ✓ <i>Searching for information providing hope</i> 	<p>Linda: Cautiously holding on to the diminishing threat of death</p> <p>Time 1: Trying not to give up regardless of low odds</p> <p>At the time of the first interview, Linda seems to be overwhelmed with the severity of her situation when she is offered only chemotherapy. Her loss of hope seems to be magnified by a disappointing interaction with her clinician. With the encouragement of her partner, she embraces the hope which the surgery can offer, despite a lack of guarantees.</p> <ul style="list-style-type: none"> ✓ <i>Perceiving option of chemotherapy as not a real option because of previous experiences</i> ✓ <i>Looking for chances of survival regardless of the odds</i> ✓ <i>Feeling unimportant as a result of broken promises from clinician</i>

Table 5.4.1 Continued Cross Case Longitudinal Superordinate Theme 1: Making sense of the diagnosis

Cross Case Longitudinal Superordinate Theme 1: Making sense of the diagnosis		
<p>Time 2: Managing the feeling of not being cancer free</p> <p>Similarly to the first interview, Kate seems to struggle to have faith in clear scans as she is experiencing a number of symptoms. As a result, she seems to consider the possibility of her cancer returning. However, she tries to use her previous experiences and reassure herself by focusing on treatments available to her if her fears become a reality.</p> <ul style="list-style-type: none"> ✓ <i>Preparing for different negative scenarios</i> ✓ <i>Managing her anxiety in-between scans</i> 	<p>Time 2: Looking into the extended future</p> <p>Over the course of time since the first interview, Chis has had two clear scans and regained physical strength. This seems to allow him to focus on the future free of cancer. He contrasts his initial prognosis with the current situation, which provides him with further reassurance.</p> <ul style="list-style-type: none"> ✓ <i>Embracing the lessening threat of cancer</i> ✓ <i>Looking into the extended future with improving prognosis</i> 	<p>Time 2: Balancing the lack of immediate threat against an uncertain future</p> <p>By the time of the second interview, Linda has had a clear scan and regained some physical strength. She reflects on her journey after receiving news of recurrence: from being offered only chemotherapy, then offered surgery and finally having a clear scan. She does not seem to look into the future; however, she celebrates the lack of immediate threat, which was the main focus at the time of her first interview.</p> <ul style="list-style-type: none"> ✓ <i>Celebrating temporary lack of need for treatment</i> ✓ <i>Perceiving being alive due to going private</i>

Table 5.4.1 Continued Cross Case Longitudinal Superordinate Theme 1: Making sense of the diagnosis

Cross Case Longitudinal Superordinate Theme 1: Making sense of the diagnosis		
<p>Johanna: Hoping for slower progression while facing a terminal diagnosis</p> <p>Time 1: Trying to regain hope for having more time after being told</p> <p>At the time of the first interview, Johanna describes the loss of hope for the future, following the diagnosis of recurrence. This is related mainly to the severity of the situation as well as the way she was informed about the diagnosis. She tries to regain hope by focusing on the number of chemotherapy options available to her.</p> <ul style="list-style-type: none"> ✓ <i>Previous experiences and understanding magnifying the shock</i> ✓ <i>Breaking bad news as emotionally overwhelming</i> ✓ <i>Navigating between hope and despair in light of initially conflicting picture from medics</i> ✓ <i>Trying to hold on to hope for treatment working for a long time</i> 	<p>James: Facing an unpredictable disease until the end</p> <p>Time 1: Trying to make sense of changing meaning of the diagnosis</p> <p>At the time of the first interview, James describes at length the emotional impact of being confronted with a constantly changing situation and prognosis. This in turn makes him doubt his current situation, with symptoms leading to ongoing worries about worsening of his prognosis.</p> <ul style="list-style-type: none"> ✓ <i>Enduring the emotional turmoil of constantly changing prognosis from health care professionals</i> ✓ <i>Constantly doubting the accuracy of their prognosis</i> 	<p>George: Having to face terminal diagnosis in an untrustworthy system</p> <p>Time 1: Trying to relocate faith in the system and more years ahead</p> <p>At the time of the first interview, George faces a terminal prognosis while being uncertain about the effectiveness of the chemotherapy he has been receiving. He describes at length his initial disappointment in the health care system, and how he has now partially regained his confidence in it.</p> <ul style="list-style-type: none"> ✓ <i>Feeling failed by the system causing distress</i> ✓ <i>Trying to locate trust in supportive health care professionals</i> ✓ <i>Having to accept the uncertainty about his prognosis while knowing the final outcome</i>

Table 5.4.1 Continued Cross Case Longitudinal Superordinate Theme 1: Making sense of the diagnosis

Cross Case Longitudinal Superordinate Theme 1: Making sense of the diagnosis		
<p>Time 2: Managing concerns about future disease progression</p> <p>By the time of the second interview, Johanna has had two scans, which indicated that the tumour was reduced, following which she had a break from the treatment. She tries to use this as a reassurance for the effectiveness of the treatment in the future. However, this is difficult as she worries about the upcoming scan. In the context of the uncertainty of her situation, she engages with thinking about the possibility of dying.</p> <ul style="list-style-type: none"> ✓ <i>Escalating anxieties about being denied treatment in the future</i> ✓ <i>Managing her worries about the process of dying</i> 	<p>Time 2: Being faced with an accelerated dying process</p> <p>By the time of the second interview, James seems to face even greater uncertainty when he cannot be sure of any aspect of his situation. While at the time of the first interview he seems to have some hope for the future, now he has to accept a terminal diagnosis but still cannot be sure of the extent of the severity of the situation. He struggles to deal with it, and tries to find information about aspects of his illness he can trust.</p> <ul style="list-style-type: none"> ✓ <i>Being confronted with the worsening prognosis</i> ✓ <i>Balancing ambiguity about one area with lack of bad news in another</i> ✓ <i>Having to accept the uncertain outcome of the treatment</i> 	<p>Time 2: Suspiciously accepting the treatment from the system in certainty of terminal diagnosis</p> <p>Over the course of time since the first interview, George seems to have lost his faith in the health care system again. He reflects on the treatment decisions which were made and not being able to understand them, which lead to a loss of trust. Despite his lack of trust, he accepts his treatment as this is fuelled by his will to live.</p> <ul style="list-style-type: none"> ✓ <i>Accepting various treatments regardless of feeling experimented on</i> ✓ <i>Enduring uncertainty about future treatment options</i>

The extent of similarity between the initial diagnosis and recurrence varies between participants. Kate and Chris are both offered surgery following the diagnosis of recurrence and are slightly reassured by the familiarity of this treatment. However, for Chris, this familiarity is limited by different treatment arrangements and for Kate by worries about being able to survive the surgery. However small, the feeling of familiarity does not seem to last long, as following completion of the treatment, while hoping for clear scans, worries about disease progression seem to come to the forefront. In contrast, the extent of similarity for Linda is less than Kate and Chris as while she had undergone surgery for the initial diagnosis, she is offered chemotherapy only following the recurrence. When offered chemotherapy only, based on her previous experiences she deems it as ineffective and consequently seeks the familiarity of treatment by pursuing a second opinion and, with time, is able to be offered surgery. Although this initial making sense process is different from Kate and Chris, afterwards Linda seems to also focus on disease progression and hope for clear scans. This later approach and emphasis on balancing hope for clear scans and worries about further recurrence, is therefore shared between Kate, Chris and Linda. Others, such as James, George and Johanna, have even less familiarity between their previous and current situations as they are offered new and different types of treatments. As a result, these participants struggle with this lack of familiarity and thus their new situation. However, like Kate, Chris and Linda, with time, the importance of this lack of familiarity seems to diminish. Instead, James, George and Johanna focus on using their most recent experiences as a way of monitoring progress. However, certain aspects such as previous disappointment with a health care system can still play a role in how the current situation is perceived.

Kate and Chris, who both underwent surgery following a diagnosis of recurrence, talk initially about the significance of the initial diagnosis. For Kate, this is mainly related to how she perceived the risk of recurrence following completion of her first line of treatment and the impact of that on her actions, and later on how she perceives her chances of surviving the treatment offered at the time of recurrence. For Chris, this is related to the impact of different to the initial diagnosis treatment arrangements at the time of recurrence. With time, while Chris seems to be slowly reassured by clear tests and regaining his physical strength and is able to look into the

extended future, Kate does not seem to be reassured, which may be related to her experiencing ongoing symptoms. However, we can see how she seems to regain hope for being able to live with cancer despite her fears of another recurrence.

During her first interview, Kate reflects on the time leading to the diagnosis of recurrence, especially experiencing symptoms following initial treatment and how this impacted on her reaction to the news itself. Her anxieties about the possible return of her cancer fuelled her determination to maximise her chances of survival, with an exercise regime being one strategy she adopted. Recognising the possibility of cancer returning, possibly because of experiencing ongoing symptoms following the completion of treatment, also motivated her to establish a support network with health care professionals. Here, Kate (who had experienced delayed initial diagnosis and was told about recurrence whilst on her own) describes how she made almost a contingency plan for future problems:

Because the way it was handled with my initial diagnosis, between the GP and the way I was told at the hospital I asked my specialist nurse, if there were further problem, would she tell me. I didn't want to hear it from anyone else.

In his interview, Kate's partner Michael also describes the time leading to the initial diagnosis but mainly in relation to the information he received from a friend who is a nurse who warned him about the risk of his wife developing a recurrence. It seems that while Kate seemed to be partially expecting a return of cancer as she was experiencing symptoms, for Michael it was mainly because of information he had received about the disease.

When she was going through follow up tests, Kate had received a phone call from the nurse saying that there was "a shadow on her liver". She seems to approach this information suspiciously and see it as a way of saying that her cancer had in fact come back, which in turns seems to reduce the impact of news for Kate when she finally receives it. She seems to compare the recurrence with the initial diagnosis, which was "a shock" to Kate. She describes the experience of recurrence as what it was not like, rather what it was like. This may suggest that the shocking nature of the initial diagnosis was very important to Kate:

I said I guessed that what I was told over the phone was a lot of baloney, just to try to keep me calm, which I appreciate, I actually appreciate what they did. I knew that there was something, I was not shocked. I wasn't sort of sat there in shock. I was not wanting to hear what I was hearing but I was not in a panic, it wasn't coming out the blue this.

It appears that despite different ways of being warned about the possibility of developing recurrence, both Kate and Michael seem to describe a diagnosis of recurrence as less shocking than the initial experience. The delivery of news by, as described earlier, the nurse of her choice seems to lessen the negative impact of the news for Kate. The nurse's approach seems to contain her distress and allows not becoming "too or more upset". Kate also uses the information from the nurse to balance the impact of the news. She draws reassurance from being offered surgery and takes this as indication of "doing something". Secondly, she compares herself favourably to other people who get tumours:

She told me that it was just the one tumour that was in my liver and I asked her could anything be done and she said yes [...]. They discussed it and in the view here at X [hospital] it was operable and it was still small. I suppose other people are getting tumours in the livers and mine was small and it was just one. I think I felt a sense of relief. [...], just from hearing that something could be done.

This feeling of being reassured by being offered surgery does not seem to last long. We can see here how Kate tries to negotiate the information about the survival rates of the surgery she is going to have. She seems to use her previous knowledge about surgery to rationalise her decision about not learning about survival rates of the surgery for the recurrence. We can see that while she does not seem to want to know the prognosis because of worries that it could be worse than expected, she also tries to reassure herself that in fact it could be not "as bad as the bowel surgery". Also, listening to the information again appears to be too much for Kate as she already "knows it" and not hearing it again becomes one of the ways she protects herself from potentially devastating news:

And when it came to my liver surgery at X [hospital], I knew, I knew that that information would have to be given to me again and I insisted that, OK, it was perhaps not as bad as the bowel surgery but I didn't want to hear it again, so I insisted that I knew it. I didn't want to hear it again. Knowing it was enough- I didn't want them to repeat it again and they respected that.

The uncertainty of her illness and future seems to continue for Kate following the completion of the treatment for recurrence. Having had clear scans, she does not feel free of the threat of cancer and is not able or does not want to celebrate. Experiencing some symptoms and ongoing tests seem to contribute to this feeling. In fact, she seems to perceive her situation as being in limbo when the situation is only stable at this moment and can be changed by any of the upcoming tests:

I don't know where I am at the moment: the results from scans and blood tests that I had until now seem good but I have another scan to come and I have the scope down and I have the result of that to come.

Kate's partner also seems to be preoccupied with the symptoms and their meaning. While he seems to be partially reassured by clear scans, they are not enough to relieve his worries.

By the time of the second interview, Kate has had another clear scan, but she seems to be occupied by worries about a further return of cancer, mainly related to her experiencing symptoms. We can see almost a gradient in the different scenarios she prepares herself for. She seems to accept the symptoms as long as they do not mean cancer. She then moves to the second scenario. She could accept the news of another recurrence, as long she is offered treatment. She differentiates between "cancer you can live with" and cancer which "becomes the death sentence". It is possible that being offered surgery at the time of the initial diagnosis and recurrence, allows her to make that distinction:

I don't feel free of it. I feel there's something there, but like I said it's not worrying me, so long as, in a sense I suppose as long as there's nothing showing up, there's nothing, you know, I'm fine with that, that's brilliant. But if something does crop up on the likes of the

scans I've just had, so long as they can deal with that- I feel OK. [...] So long as I, if I've got cancer, as long as I can live with it, and I'm OK, as long as it doesn't become one of these, a bit of a death sentence, I'm fine.

At the time of the second interview, Kate's partner also seems to focus on the presence of symptoms, which cause substantial anxiety. His anxieties are further fuelled by negative experiences related to cancer in his family. Concerns about the meaning of symptoms are also reflected in Kate's approach to monitoring. She expresses her need for more frequent follow-ups to alleviate her anxieties about the undetected disease progression. Kate tries to contain the anxiety by trusting her clinician. This trust seems to extend only to the next appointment though and the symptoms seem to be dominating her thinking:

Those are the main symptoms that I seem to be getting, and that's what makes me feel that there's something not quite right in my body. I've got faith in my oncologist, so what they tell me will, that will keep me going until the next appointment. It's just generally how I'm feeling.

Chris also talks at length about the time leading to diagnosis and treatment. The distress and worry about a possible recurrence is fuelled by repeated tests as part of the follow up. They seem to act as a trigger of concerns and seem to be part of the diagnosis period, which in the end confirm his fears:

I have been having all the scans so I knew that something was not right.

Following the news, he also uses his experiences of the initial diagnosis as a comparison, namely in relation to waiting times. Here, the lack of similarity between the initial experiences and recurrence triggers anxiety as Chris perceives a striking contrast between efficiency of the initial diagnosis and lack of it at the time of recurrence. The perception of the system not meeting his needs seems to magnify the distress. Chris finds waiting very difficult as he wants to "get rid "of cancer as soon as possible. The urgency seems to be fuelled by the fear of the disease progression and in fact as determining his survival:

When you were eventually told we can sort this, that is great, but I wanted that sorted tomorrow, not we can fit you for operation in three months' time because in the meantime I am sat with this fear that this awful thing is growing inside of me and is getting worse. (...). It is just not quick enough, once they, the second cancer, it wasn't quick enough to get the operation.

While Chris' distress seems to revolve around the perceived lack of efficiency in dealing with his situation, his partner Louise describes at length the difficulties she had in coming to terms with a diagnosis of recurrence, with the option of surgery not lessening the distress. With time, this seems to change and she is able to focus on the hope provided by being offered this mode of treatment. Having gone through surgery, Chris has had a clear scan, but similarly to Kate, he initially takes a rather cautious approach to the good news. He balances the good news of the clear scans against the ongoing nature of the tests. It seems that one test is not sufficient and he has to endure waiting for another to gain much-needed reassurance:

I mean at the moment the prospects are quite good. We hope after today's chat but we, this is ongoing thing with the check-ups and the scans. So we get to find out what happens after the next one.

Louise also seems to balance lack of guarantees for the future with a celebration of the first scan and they both seem to wait for the second scan as an indication of the hope for the future. In the context of the uncertainty he faces, Chris describes his need for information about his prognosis. He describes here how he approached his GP for more details about his situation. We can see how his need for information is negotiated between Chris and his GP, as the focus on accuracy seems to be blurred with the need for hope. While Chris seems to perceive the information from the GP as not being helpful, as not tailored to his situation (i.e. age), he seems to refuse it mainly as it does not provide much hope. We can also see the interpretation of the prognosis he is provided here as well where 5% in five years is interpreted as one year of being alive. The information provided from his GP is also set against the most recent prognosis from the oncologist, which Chris seems to see as the best within the constraints of his current situation:

So for instance, I actually asked a doctor, in my own practice I need to know what are the chances of me being here in 5 years' time and his answer was after he did a little bit of research was 5%, but he didn't then turn around and said that is 5% of all the people who have this type of cancer you have got. [...]. He didn't qualify with that bit so then it suddenly becomes quite frightening that in 5 years' time, 5% chance so probably I have sort of year or so left and that is frightening. My consultant told me today that it is improving, and certainly 50-50 that I will be here in 10 years' time so that is as good as it gets at the moment.

By the time of the second interview, Chris has had two clear scans. He now balances feeling positive with the previously adopted cautiousness. Regaining physical strength has also contributed to his feeling positive and not needing any further treatment at this time:

I also have had two clear scans since we last met which is fantastic [...]. It is wonderful but it is still early days so my actual condition has changed in the matter that I have got a lot of energy that I had then.

Chris also seems to embrace his improving prognosis by reflecting on the change of his situation from the point of news of recurrence to the current moment. He recalls the prognosis he was given initially by his GP to show the extent of the improvement in his survival. In fact, we can see how he is looking into the extended future, when he discusses how he is going to be when the 5 years of the close monitoring will finish:

Well initially going back I was given that it could be as low as 5% survival rate over 5 years and that dramatically, I have been told that has improved now, so much so that he virtually fully expects to see me here after a 5 year period and at 5 years basically, there is no need for any check-up anymore.

While both Chris and his partner Louise seem to take great comfort from another clear scan, only Louise actually perceives the situation as beating cancer. While Chris seems to mention a 5-year period thus indicating that he also hopes for long-term future, it is Louise who frames it as beating cancer. It might be that it is still too difficult for Chris to verbalise his hopes in the same way.

In contrast to Kate and Chris, Linda is told initially that she is not able to have surgery, but later on finds out that she might. Similarly to other participants, she also seems to be drawing on her initial experiences of colorectal cancer to make sense of the diagnosis. Despite the fact that she also had surgery for the initial diagnosis, she perceives the ineffectiveness of chemotherapy at initial diagnosis as the basis for refusing this as an effective treatment for recurrence. As she perceives it to have been ineffective as the initial line of treatment, she sees chemotherapy for recurrence as in fact a “waste”:

He [surgeon] didn't think that the operation was possible, so the only thing he offered was chemotherapy. And I said to him, well it didn't work the first time, so it was just a waste.

With help and encouragement from her husband, Anthony, Linda decides to “go private” for the second opinion and as a result, she is told that she might be eligible for surgery, which in the end is carried out within the NHS. The rationale behind the decision to give herself a chance is clearly visible, when the offer of chemotherapy is not even considered as a real option by Linda. Surgery, the only treatment perceived as an option to Linda, seems to have an uncertain effectiveness, as demonstrated by clinician’s approach of “giving it a go”, yet still represents a chance for Linda:

They said after a couple of days, yes, we can give it a go but they are going in blind. Even this thing I didn't know if it is going to work, at least you feel that you have a chance.

I: So the decision to go private was because you wanted more options?

R: I just wanted an option.

While for Kate there was some indication of the importance of her relationship with the clinical team in giving the news, this seems to be magnified for Linda. She recalls how she was promised the phone call to discuss the results and treatment options, which she did not receive. While she recognises that she is one of the patients, she expresses her disappointment and the perceived lack of compassion from the clinician. The offer of the chemotherapy as the only treatment option seems to be the final addition to the distress of the diagnosis and its meaning:

He didn't phone me. I know everybody is busy, and everybody is as important as everybody else but he only has to pick up the phone to tell me what he decided. Two weeks later I got a letter to say that it was all he could offer me.

Linda's description of receiving news is relatively brief, when compared with her partner, Anthony. In the first interview, he talks at length about his despair following the diagnosis with the clinician's behaviour fuelling his feelings. He describes in detail how the clinician spent in his opinion little time examining his wife and quickly concluded that only chemotherapy was an option. While Anthony's partner Linda seems to be bitterly disappointed that the consultant did not telephone her as he had promised, Anthony takes it as meaning he did not regard it as worth treating her. As a result, Linda seems to struggle not only with her disappointment but also with Anthony's despair.

At the time of the second interview, Linda has had one clear scan and as a result, she is not scheduled to have any further treatment. She seems to celebrate not needing further treatment, while reflecting on the meaning of the current prognosis as well. Here, Linda describes her reaction to the explanation provided by the clinician about not having to go through the chemotherapy. She seems to hold on to the explanation provided by the clinician, which she also previously provided herself, that there is no need for chemotherapy. However, like Kate and Chris, she seems to face only temporary certainty about clear scans. She also reflects on the treatment decisions she had made when she learnt initially about her diagnosis of recurrence. While she recalls the situation, which she also talked about at the first interview, she now adds her reflection that "going private" and being able to have surgery was in fact potentially lifesaving:

I had to pay, we paid for it privately and also I had a scan which we paid for privately then but X [partner] said what price for the life, you sort of have that money for the holiday, save your pennies. [...] I probably would not have been here, well definitely wouldn't have been here if we hadn't.

Similarly to Linda, Anthony also reflects on their experience from the time the news of recurrence was received. He highlights how much the situation

has changed as she was given a chance with a surgery. This enables both of them to think cautiously about the future.

While Kate, Chris and Linda are able to undergo surgery, Johanna is not offered surgery following the news of recurrence. Similarly to the initial experience of Linda, lack of familiarity with the situation at the time of recurrence, seems to magnify her distress. There seem to be a number of factors which have an impact on Johanna's reaction. While Kate also described the time following completion of the initial treatment, she perceived her risk of recurrence as much higher, possibly because of experiencing symptoms. In contrast, Johanna seems to have adopted the identity of a survivor, also highlighted by the typical discourse of survivorship of "beating cancer". Adoption of the survivor identity seems to be related to the fact that she has had, unlike Kate and Linda, numerous clear scans. This, in turn, seems to magnify the shock of the news:

I never, ever thought that it would come back to be honest. I thought I have beaten it. I was a survivor. [...] I kept having clear scans, clear scans and then to say that it has not only come back but spread. I could not believe it was happening to me.

Johanna also reflects on her understanding of the cancer at the initial diagnosis and the information she was provided with then. Here, we can see how complex information regarding the diagnosis is negotiated by Johanna in the health care system. While she says that you are "never given a guarantee", she was also "told that she was cured". This ambivalence seems to be brought to the light when told about their recurrence.

They will never give you a guarantee but I have finished the chemotherapy. I was told: "You are cured". "Oh that is it then"- off you go, going to live again.

This understanding is also shared by her partner Alan, who is also initially overwhelmed with the severity of the situation. The shock of the diagnosis seems to be also related to the impact of symptoms on her quality of life. As before the initial diagnosis she was suffering from severe symptoms, she saw the diagnosis as a solution to her problems and almost a salvation at that time. In contrast to this, she did not experience symptoms after initial

treatment and seems to be taken by surprise with the diagnosis of recurrence, which generates a “sheer devastation”. The extent of the uncertainty and loss of hope is different for her in comparison to Kate and Chris, as she is initially told that she is not eligible for surgery and she “should put her house in order”. Not long after that, Johanna is provided with a more optimistic interpretation of the situation by the oncologist. This interpretation is constructed by the provision of new factual information, which seems to undermine the previous information. This approach is favoured by Johanna and provides her with hope:

He was absolutely blunt, he said you need to put your house in order. We sort of left feeling that there was no hope. On seeing the oncologist a week later [...], he put a slightly different slant on it: spread was only an inch, the spots were only meniscus. “We will start the chemotherapy”. I left more hopeful. You don’t want to be told that everything is hanky dory but you do not want to be told that you are going to die, get your house in order.

As, unlike for Kate and Chris, there is lack of a clear solution, namely surgery, Johanna tries to make sense of the information regarding the uncertainty attached to the effectiveness of treatment. She seems to engage in a number of strategies to reassure herself while also accepting the limitations of the treatment offered. She highlights that she has in fact two treatment options and that she is really using only the first one and how this in turn could contribute to her longer survival. The number of options she is presented with is in contrast with the lack of a guarantee about the effectiveness of that treatment. She seems to embrace the hope for the treatment effectiveness regardless of those challenges. However, this is difficult, and she ruminates about the future lack of treatments. While she looks into the future with no treatment options, she also blocks these thoughts to preserve her well-being:

The chemotherapy is working well at the moment. When it stops working I am told there is plan B, we are still on a plan A. [...] I hope that continues for some time. I mean after the first six cycles [...] it has reduced, it has not gone but it has reduced so that means extra time so we will see what the next six will bring. The doctor did not say that there is any guarantee but I live in hope [...]. When I get to

the situation when they say that all the chemo options have been exhausted, there is nothing we can offer you, I do not quite know how I will cope with that. I am trying not to think about that cause I am not there yet. It would drag me down.

While Johanna seems to seek ways to deal with her situation, she also acknowledges her worry about the future options. In contrast, her partner Alan seems to focus on the recent scan which indicated that tumor had reduced. This creates, in Johanna's opinion, problems in their relationship, as she feels unable to face the severity of the situation with Alan. This concern is not, however, shared by him. By the time of the second interview, Johanna has had two clear scans, following which she has had a break. She is awaiting the third scan to see how effective the treatment has been and to establish the progression of the disease. Johanna describes her concerns about the scans awaiting her and worries about the treatment available to her at this point. She seems to use her previous experience at the time of recurrence to fuel her hope for being able to continue treatment and builds a rationale for it against the uncertainty of the situation. She starts with saying "I can't see", which seems to hold the most certainty, then quickly moving to "I don't feel", which seems to refer to her more subjective perception and finishes the sentence with "I am just keeping my fingers crossed". This rapid movement between certainty and mere hope highlights the difficulties Johanna is facing:

I am sort of presuming really that since the chemotherapy had worked up to 6 cycles and up to the 12 cycles. I will go back on the chemotherapy regime again you know. I can't see that things progressed, I don't feel that the things has progressed significantly, so I am just keeping my fingers crossed that this what is going to happen really.

Similarly to the first interview, Johanna's partner seems to present a more optimistic interpretation of the situation. While he seems to acknowledge, though reluctantly, the uncertainty related to the next scan, there is no mention of what may happen if there is negative news. In contrast, regardless of the hopes for a prolonged future, Johanna seems to engage with the process of dying and faces some of her worries about the process. This creates further distance between her partner and herself. She tries to

draw reassurance from other people's experiences about the process of dying and describes her involvement with the hospice. While she seems to be engaged with the idea, she still distances herself from the dying, by saying "if I needed that in the future":

So I am glad that I have got that connection with the local hospice because I know that if I need them in the future, I feel comfortable going there cause I know people who work there. I know them now, I know people who work there and they are all fantastic so I would feel very comfortable to go to that sort of environment if I needed that in the future.

By the time of the first interview, James and George had experienced a second recurrence, for which only chemotherapy had been an option. Their experiences resemble to some extent the experience of Johanna's, with some aspects magnified, especially in relation to managing the fears of disease progression.

At the time of the first interview, James reflects on this overall experience of cancer recurrence as he tries to make sense of the constantly changing prognosis and information from the health care professionals. Similarly to Johanna he has to face conflicting information from health care professionals. The impact of a bad prognosis turning into a potentially good one is evident in the metaphor of "death sentences" used by James. He tries to make sense of the conflicting information regarding his prognosis and to distinguish between "real" and "fake" death sentences. Here, James talks about the situation when he was told that the tumour was not operable but after chemotherapy working very well, he was offered surgery. The paradox of this situation is visible in almost a "fake" death sentence and the psychological impact of that:

Initially, I was given too negative prognosis. [...] I have been given a death sentence when I didn't need to be. I had a number of death sentences; some of which turned out to be treatable; initially [...] it was terminal, then it turned out that they can operate.

These experiences may have influenced the way James perceives his current situation. While other participants also seem to describe the

uncertainty of the situation and how the scans are not able to provide a long lasting reassurance, for James this feeling of doubt seems to be magnified. Even when being in a relatively stable situation in between tests, James has to deal with numerous doubts regarding his situation. He seems to question his prognosis all the time:

If it is those areas, it might be in other areas. They have not actually said that but this is what I expect.

Similarly to Kate, physical symptoms also take a new meaning as they could indicate a new metastasis. Here, the pain in the neck is being compared with the previously experienced pain in the back to try to make sense of it:

I have some pain in my neck, like my back pain was, so that makes it difficult to diagnose.

In addition to these worries, James' partner, Victoria, also describes the uncertainty related to treatment options. She highlights that starting a new treatment signifies not only the changing severity of the situation but also the potential for new side effects, which in turn magnify the distress. By the time of the second interview, James sees further surgery as a very unlikely option. He understands that he faces a terminal diagnosis. However, he is still faced with a number of challenges regarding the meaning of symptoms and the treatments he is offered. While at the time of the first interview James shifted between changing prognoses from health care professionals, here we see how an apparently stable situation is challenged again. We can see the complexity of James' situation in the following extract and how certainty about one aspect is being met with the uncertainty about another. While he has to accept the inability to know what the situation is in his sacrum, he tries to balance that with a more predictable picture in relation to other areas of his body:

I have got the situation in the sacrum where we kind of don't know what is going on and the liver everything is as it was, nothing got any bigger and there is nothing new, there is nothing new on the body as well.

While other participants are also facing the uncertainty related to the effectiveness of treatment received, this can be partially resolved by the

results of the scan. Once again, James is faced with an uncertainty about the treatment he has recently received as after having radiotherapy, he is told that in fact they are not able to determine the effectiveness of the treatment because of scar tissue as a result of the treatment. We can see the extent of the uncertainty when health care professionals cannot draw any conclusions from the tests following treatment:

In terms of how effective it has been they can't tell me. It could be one or the other, it could be completely eradicated or the tumour could be completely unaffected.

In addition, Victoria also describes the impact of the treatment on day-to-day life. The unpredictability of side effects means that the family's rhythms are disrupted, which she finds difficult.

George, similarly to James, experiences a second recurrence for which he also receives chemotherapy only. While we could see the importance of the relationship with the health care professionals for Kate and Linda, George's experiences with health care system seem to be closely linked to how he makes sense of the diagnosis. George experienced delayed diagnosis initially and once he had undergone surgery, he was told that a mistake was made and as a result his cancer was not resected properly and it had grown. As a result, his frustration and disappointment with the system seem to generalise and we can see how George tries to deal with that. While he describes a global disappointment, he goes on to correct himself, praising the nurses in the end. It seems that the grief caused by the doctors is colouring the relationship with all health care professionals involved:

That is why I wasn't very happy with it and of course I am not very happy with surgeon who didn't cut the polyp out, so I am not very happy at all. Well no that is a lie, as I say, I don't have any complaints about the nurses, their manner.

In light of his initial disappointment, George tries to locate trust in other health care professionals. At the time of recurrence, he has built a trusting relationship with another clinician. This new relationship seems to be appreciated by George because of the partnership nature of it, which is in contrast to the relationship he described earlier. It seems that a good relationship with the clinician might facilitate the trust he has got in the

treatment offered or they may fuel each other. On the surface, his faith seems to be largely dependent on positive messages from the clinicians about the treatment options and extending life. We can see however, that for George, similarly to Linda, “doing all the clinician can” is important as is perceived as not giving up on him:

I have got every faith in the specialist I am seeing at the moment. He is a real nice bloke and I have every faith in that when he tells me that I could last for years, I believe him and I believe him that it could be years. And he says that if there is any problem with the chemo, he said, we will try something else. So you know, he is doing all he can. That is all I can ask for, he is doing all he can.

George, similarly to Johanna and James, also seems to be faced with uncertainty in relation to the effectiveness of the treatment against the certainty of the terminal diagnosis with scans being waited for to reveal one’s fate. While he knows that his cancer is terminal, he needs to wait to see the outcome of the treatment and the next steps for him. In the context of this uncertainty, George seems to perceive successful chemotherapy treatment as the only hope he has left:

I: What is the aim of the chemotherapy of this chemotherapy?

R: To shrink the tumours. They said it is terminal. I said, you know, how long have I got. They can’t give me any date cause the, I had CT, no CT, fMRI scan a few weeks ago and they are waiting for the result to come back to see if the chemo is working to, see if the chemotherapy had shrunk the tumour in the pelvic region. Well, all I hope is that this chemo is working, that is all I can hope for.

By the time of the second interview, George seems to have lost some of trust he had regained in the system that he described at the first interview. He seems to think that because of his age, he is experimented on with the treatment. Here, George describes how he tries to make sense of uncertainty regarding the effectiveness of the treatment. He seems to attribute his age to being offered different treatment options. This seems to be his perception of the situation, based on a “feeling”, which may suggest that it’s based on his expectations towards the system:

I just feel, it's a teaching hospital, I just feel that at times they tend to experiment with you. I'm coming up to 72, I just feel that we'll try this and see if that works, you know, it's more experimenting with you. I'm sure of it, that's what I feel. I mean perhaps they're not, I don't know.

George also reflects back on decisions related to his care. The perceived delay in attending to his tumour is questioned by George. It seems that lack of information provided at the stage of choosing treatment is perceived as in fact “experimenting”. The unanswered questions, even from the time of the initial diagnosis, seem to still have an impact on how the current situation is perceived:

Because going right back, when I had the first operation they left some of the polyp in, and rather than have an operation straight away and remove the remaining polyp, they decided that they will do radiotherapy, so I had radiotherapy and about six months later then I had the operation to take the remainder of the polyp out, now why didn't they take the polyp out straight away.

Regardless of these concerns, George also seems to accept all the options recommended to him. Not only he is reluctant not to take on the clinician's advice, but seeks it himself by asking for it. This seems to be related to his acknowledgement of a terminal prognosis and his will to live but taking on an expert's advice does not seem to mean trusting him/her:

I have to go by what he says, he's the expert, not me, and that's what I do, if he said I recommend this treatment I wouldn't say no, I'm not having it, I would go along with it, no matter what, I've got to accept that he knows what he's doing, whether he's experimenting on me or not.

5.4.2 Part B- Cross Case Longitudinal Superordinate Theme 1: “Making sense of the meaning of diagnosis”

The first theme: *Making sense of the meaning of the diagnosis* describes the constantly changing prognosis, the treatments available to patients, as well as their understanding of the situation. I will discuss how the similarity between the experience of initial diagnosis and recurrence and lack of it

was used to make sense of the news of recurrence, treatment options and their prognosis.

The emotional impact of hearing the news of recurrence on patients is well established. In the current study, patients described a number of emotions following hearing the news including shock, devastation, fear and feelings of hopelessness. The impact of receiving news has been shown in previous qualitative studies exploring the experiences of recurrence in non-colorectal cancer groups, which highlighted a range of emotional responses following patients' diagnosis of recurrence, including shock, fear, anger, devastation and hopelessness or even guilt and shame (Griffiths et al., 2008, Mahon and Casperson, 1997, Misra et al., 2013).

In fact, the initial diagnosis was an important reference point for the patients, which could have had an impact on the emotional meaning of the diagnosis of recurrence. This seemed to have been mediated in a number of ways. Following the initial diagnosis, patients drew reassurance from scans that their situation was improving. They seemed to negotiate an understanding of what it means to "be cured" with health care professionals, who, as described by patients, did not provide guarantees but also discharged them, which may have suggested to them being in fact "cured". Recovering physically from the initial operation and resuming previous activities were also signs of "beating cancer". This in turn facilitated adopting the identity of a survivor, which seem to magnify the shock of the return of cancer. In contrast, experiencing symptoms following initial treatment was a warning sign for some patients and triggered thoughts about disease recurrence and consequently, seems to lessen the impact of the news. In the time leading directly to the news of recurrence, changes in how the results of the regular follow-ups were delivered acted as a warning sign about the potentially negative news.

These issues have been discussed to a certain extent in the context of follow-up programmes and self-monitoring, particularly in relation to what the aims of the follow-up appointment should be (Lewis et al., 2009). One study exploring the views of colorectal cancer patients on the follow-up revealed that participants felt reassured and optimistic about the future following clear tests also highlighting that fears of recurrence were most common immediately following the completion of primary treatment (Lewis

et al., 2009). Other studies also highlighted the importance of follow-up appointments in providing patients with knowledge on potential signs of recurrence. A study exploring the views of patients with colorectal cancer about follow-up revealed that only 21% were aware of what the potential signs of recurrence were, with 64% stating their desire to know more (Papagrigroriadis and Heyman, 2003). This is a rather complex issue as while the identification of symptoms was found as facilitating detection of recurrence in some studies exploring the experiences of cancer recurrence (Coward & Wilkinson, 2000, Elit et al., 2010, Maher & De Vries, 2011, Sarenmaln et al., 2009), others have shown that even awareness of symptoms may not lead to the diagnosis as patients may initially attribute them to non-cancer causes (Coward and Wilkie, 2000, Mahon and Caspersen, 1997, Howell et al., 2003). Previous studies also highlighted how the effects of the previous and current treatment may accumulate and in turn, have a significant impact on patients' well-being (Halliburton, 1992, Munkres et al., 1992). It seems that to date, studies looking at patients' experiences of follow-up has highlighted mainly the importance of clear scans and physical recovery from patients, while studies of patients experiences of recurrence have drawn our attention to the awareness of potential symptoms of recurrence and length between initial and current treatment. The current study highlights how all these factors could play a role of making sense of diagnosis at the time of recurrence.

The type of treatment offered to patients is also an important aspect of the diagnosis of cancer. In the current study, the diagnosis of recurrence initially signified an important transition from hoping for being cured to a possibility of approaching death. Similarity between the initial treatment and treatment offered at recurrence was important for patients in making sense of the meaning of the treatment and prognosis.

Patients who were offered only chemotherapy found it difficult to accept, often because of the lack of similarity in treatment between initial stage and recurrence. This lack of similarity could be further magnified by negative experiences with care or primary treatment, when patients who experienced disappointing relationships or care at initial diagnosis, saw the system as less trustworthy at the time of recurrence. Delayed diagnosis, or even perceived incompetence of surgeons leading to unnecessary operations were particularly challenging and led to the loss of trust in the

system. Equally, broken promises were perceived as being given up on and not being worth attention from the clinical team. For some, only with time was there a shift from hope for surgery to hope for continuing on the chemotherapy regime, while others focused mainly on having contingency plans, mainly other chemotherapy regimes, regardless of the guarantees about its future effectiveness. However, continuing with treatment was very important as it seems to signify the active approach of tackling the disease and “doing something” as the alternative could be mere symptom management. While not being offered surgery seemed to magnify distress, as being faced with unfamiliar situation, being offered surgery provided only some reassurance. This reassurance seemed to be halted by lack of similarity in other areas such as perceived inefficiency at time of recurrence in comparison to the initial diagnosis or fear for similarity with previous experiences such as knowledge of poor survival rates. While the majority of previous studies at the time of recurrence showed that people saw the aim of the treatment as changing from providing cure to controlling symptoms, prolonging life or controlling cancer (Ekwall et al., 2007, Elit et al., 2010, Mahon and Casperson, 1997, Sarenmaln et al., 2009), one study highlighted that patients who were able to have surgery, regardless of the lack of guarantees for cure, felt that they were given a chance of survival, in contrast to patients who were offered chemotherapy only (McChahill et al., 2003). The perception of patients in the current study also highlighted that patients’ experience of recurrence differ and may be largely dependent on the treatment options offered. However, the current study also emphasises that in the initial process of appraising the potential effectiveness of treatment, participants were taking into account a number of factors.

This was however even more complex for patients who were not initially offered surgery. Assessing their eligibility for surgery or other treatments seemed to be ongoing and patients were faced with a constant need to adjust to changes. Some of these changes were related to the treatment offered, when patients were initially given only chemotherapy but later on, they became eligible for surgery. Similarly, they often negotiated between the changing interpretation of the situation between clinicians, when some offered hope whereas others did not. The move between hope and loss of hope was challenging and hindered making sense of the implications of the diagnosis. This was magnified for patients with further recurrences. This

issue has been only to a certain extent highlighted in previous studies, which largely tended to describe the process of assessing treatment options as a one-off, rather than an ongoing one. Others highlighted that previous experiences of treatment being effective or achieving remission facilitated hope for the same outcome at the stage of first or further recurrences (Maher & De Vries, 2011, Mahon and Casperson, 1997), thus drawing the attention to the fact that patients see their treatment options as fluctuating. It seems that while previous studies described the issue of uncertainty as related to treatment outcome following the news of recurrence, this study highlights the complexity of the situation patients may face.

Relationship with the clinical team was described at length during the interviews. In fact, it could either magnify or lessen the emotional impact of the diagnosis. The way the information about the recurrence was delivered was also important and providing information in an insensitive way and leaving patients without hope, especially for patients not being able to have surgery, was seen as particularly negative to the relationship. On the other hand, providing information in a sensitive way was appreciated by patients. The centrality of news giving was recognised in other studies, which highlights the significance of appropriate communication at this time (Ekwall et al., 2011, Maher and De Vries, 2011, Step & Ray, 2011).

Similarly to the initial diagnosis, patients were monitored regularly to assess the effectiveness of the treatments they were receiving. Time between appointments was difficult as patients were constantly managing anxiety about possible disease progression. Patients who were offered surgery perceived a clear scan as a chance for a solution to the situation and with time, it in fact provided some hope for a cancer-free life or a possibility of living with cancer, even if they were experiencing symptoms. Their recent experiences seemed to provide some reassurance that it is possible to have a clear scan following a recurrence. This issue has rarely been explored previously; one study highlighted that patients who had experience of a previous recurrence, had the belief that remission was once more possible reinforced (Mahon and Casperson, 1997). Patients, who were offered chemotherapy only, struggled with an ongoing uncertainty regarding the scans, which was mainly related to the current

treatment regime. They used their recent experience of the treatment to monitor their progress, by comparing how much the disease has progressed since the last scan. Those who were not able to have surgery also seemed to question their previous, possibly naïve, understanding of cancer, and anxiety around disease progression meant not being offered any treatment. This in turn triggered worries about the process of dying. The issues around uncertainty of the future and worries around disease progression were highlighted in other studies, where changing treatment regimens meant that patients had to adjust their expectations. One previous study also highlighted that patients' belief in other treatment options provided what they described as an "illusion of safety", which helped participants cope (Maher & De Vries, 2011). Others described the fear of disease progression more in relation to its impact, for example loss of function and dependence on others (Vilhauer, 2008). The current study showed that the process of managing fears of disease progression was quite complex and participants used their recent experiences to make sense of it.

5.4.3 Part A- The Cross Case Longitudinal Superordinate Theme 2: *"Trying to negotiate the place of cancer in one's life"*

The Cross Case Longitudinal Superordinate Theme 2: *"Trying to negotiate the place of cancer in one's life"* describes the impact the diagnosis of recurrence cancer has on patients' day-to-day life and the approach they have taken in dealing with this. Participants experience a different extent of physical suffering as a result of treatment and have to face either temporary or permanent loss of the body they used to know. This in turn means that they are facing either temporary or permanent losses to their previous lives.

On the surface, physical suffering seems to influence the centrality of cancer presence in patients' lives and their approach in dealing with this. However, this is not always the case. Firstly, the severity of the symptoms does not always correspond with the severity of the prognosis; participants who do not experience ongoing symptoms are facing terminal diagnoses, while participants who are experiencing ongoing symptoms are deemed to be doing well. Consequently, symptoms can hold different meanings for participants. Alongside the severity of the symptoms, the frequency of

physical suffering is also important. Regaining of physical strength and intermittent periods of lack of symptoms can mean for the participants that they are able to be part of their pre-recurrence lives; for some this is not possible and the daily routine is largely focused on the treatment and ongoing recovery from it. As a result, participants negotiate the meaning of their physical suffering or lack of it in relation to their overall situation.

The diagnosis of recurrence, including physical suffering, also has an impact on participants' overall approach to life. It means that previous needs and priorities are carefully evaluated by participants. For some this can lead to a change of direction and longing for previously unrealised dreams, while others miss their previous lives and describe the impact of recurrence on their previous quality of life.

As previously described in the Methodology chapter, Table 5.4.3 sets out the Cross Case Longitudinal Superordinate Theme 2 and then, for each patient, their individual within case Longitudinal Superordinate Theme, together with their individual Superordinate Theme at Time 1 and at Time 2, and Subordinate themes identified.

Table 5.4.3 Cross Case Longitudinal Superordinate Theme 2: Trying to negotiate the place of cancer in one's life

Cross Case Longitudinal Superordinate Theme 2: Trying to negotiate the place of cancer in one's life		
<p>James: Enduring physical suffering while giving hope for cure</p> <p>Time 1: Enduring cancer treatment while maintaining hope</p> <p>At the time of the first interview, James describes at length the severity of the side effects of the treatment he is receiving. They have significant impact on his ability to participate in day-to-day activities. While he still hopes for the offer of surgery, his physical suffering with the current treatment regime makes him question his ability to continue with it.</p> <ul style="list-style-type: none"> ✓ <i>Enduring slow recovery following treatment</i> ✓ <i>Slowly reaching the limits of physical suffering</i> 	<p>Linda: Slowly regaining her body allowing her to re-join life</p> <p>Time 1: Losing a capable body following treatment</p> <p>At the time of the first interview, Linda faces a slow recovery following the surgery. She is unable to resume her activities; however tries to be positive about her recovery and uses her previous experiences to reassure herself. Despite trying to maintain a positive attitude, she feels overwhelmed by having to deal with a stoma, which she finds embarrassing and humiliating.</p> <ul style="list-style-type: none"> ✓ <i>Having to take a step by step approach when recovering from surgery</i> ✓ <i>Attempting to be positive about her recovery against challenges</i> ✓ <i>Struggling to adjust to stoma</i> 	<p>Chris: Focusing on regaining control of his body to be part of pre-cancer life</p> <p>Time 1: Having a fragile body restricting his life</p> <p>At the time of the first interview, Chris describes at length the negative impact of having unpredictable bowel movements. This in turn prevents him from undertaking previously achievable activities. He tries to manage his situation by significantly reducing his food intake. Despite the difficulties, he believes that his symptoms will improve and he will be able to return to his previous life.</p> <ul style="list-style-type: none"> ✓ <i>Experiencing bowel problems preventing him from re-joining life</i> ✓ <i>Making attempts to regain his previous life</i>

Table 5.4.3 Continued Cross Case Longitudinal Superordinate Theme 2: Trying to negotiate the place of cancer in one's life

Cross Case Longitudinal Superordinate Theme 2: Trying to negotiate the place of cancer in one's life		
<p>Time 2: Enduring life as a demanding rollercoaster until his death</p> <p>While at the time of the first interview James questioned the limits of physical suffering, by the time of the second interview he seems to be mainly focused on prolonging his life. He still experiences severe side effects but is willing to sacrifice his quality of life to be able to live longer and he actively explores different treatment options. Nevertheless, the treatment regime takes its toll and he describes his wish for a break from the relentless physical suffering.</p> <ul style="list-style-type: none"> ✓ <i>Enduring slow recovery from acute side effects following new treatment</i> ✓ <i>Accepting suffering from treatment whatever the cost</i> ✓ <i>Giving up hope for treatment replaced by longing for breaks from treatment</i> 	<p>Time 2: Wanting to embrace her recovery regardless of challenges</p> <p>By the time of the second interview, Linda has regained some physical strength, which enables her to slowly return to her activities. In comparison to the first interview, she seems to have more realistic expectations towards her physical abilities yet still rejects the sick role in her family. Similarly to the initial interview, she struggles with having stoma, which seems to be very difficult to accept.</p> <ul style="list-style-type: none"> ✓ <i>Managing her physical resources to facilitate recovery</i> ✓ <i>Taking control of returning to previously unavailable activities</i> ✓ <i>Seeing the consequences of stoma as not belonging to normal world</i> 	<p>Time 2: Trying to regain control over his body to be part of normal life</p> <p>By the time of the second interview, Chris' efforts to regain his previous ways of living, also described at length at the time of the first interview, were to some extent successful. He was able to return to work, which seems to be an important step in his recovery. Despite having food regime even stricter than previously, he rejects having a stoma as he believes that with time, he will be able to regain his previous level of functioning.</p> <ul style="list-style-type: none"> ✓ <i>Making attempts in returning to pre-cancer life regardless of challenges</i> ✓ <i>Facing losses to his quality of life</i> ✓ <i>Trying to regain control over bowel movements</i> <p><i>Rejecting stoma as an option as limiting life</i></p>

Table 5.4.3 Continued Cross Case Longitudinal Superordinate Theme 2: Trying to negotiate the place of cancer in one's life

Cross Case Longitudinal Superordinate Theme 2: Trying to negotiate the place of cancer in one's life		
<p>Kate: Struggling to find a balance between pre- and post-cancer life</p> <p>Time 1: Being faced with the fragility of life</p> <p>At the time of the first interview, Kate seems to be preoccupied with worries about her symptoms, which she fears may mean another recurrence. While scans should provide some reassurance, they also act as a reminder of the fragility of her situation. However, while small changes are possible, being faced with an unpredictable future means that she is not able to have new long-term plans, which she finds challenging.</p> <ul style="list-style-type: none"> ✓ <i>Being reminded of the threat of cancer by each scan</i> ✓ <i>Being determined to make the most of the allowed time while accepting loss of dreams</i> 	<p>Johanna: Being reminded of dying by physically challenging times</p> <p>Time 1: Attempting to maintain emotional balance on day to day basis</p> <p>At the time of the first interview, Johanna describes her attempts to regain emotional balance after diagnosis of recurrence. She seems to focus on the present to be able to deal with the situation. This strategy seems to work relatively well for her. However, intermittent physical symptoms become a reminder of the severity of her situation and thus bring not only physical but also emotional suffering.</p> <ul style="list-style-type: none"> ✓ <i>Disengaging with the future</i> ✓ <i>Suffering being a reminder of her condition</i> 	<p>George: Trying to continue with his previous life as long as possible</p> <p>Time 1: Being determined to continue with his previous life</p> <p>At the time of the first interview, George is determined that cancer does not take over his life. He continues with his previous routines as much as possible which is enabled by not experiencing many side effects from his treatment. Despite his need to maintain his previous rhythm of life, he describes some losses in his day-to-day life following diagnosis of recurrence.</p> <ul style="list-style-type: none"> ✓ <i>Experiencing mild side effects following treatment cycle</i> ✓ <i>Being determined for cancer not to take over his life</i> ✓ <i>Facing losses to his previous life</i>

Table 5.4.3 Continued Cross Case Longitudinal Superordinate Theme 2: Trying to negotiate the place of cancer in one's life

Cross Case Longitudinal Superordinate Theme 2: Trying to negotiate the place of cancer in one's life		
<p>Time 2: Struggling to re-join life outside cancer</p> <p>By the time of the second interview, Kate's concerns about finding new meaning in life seem to be magnified. While she enjoys being part of cancer charities, financial concerns come to the forefront. She also seems to focus on the loss of certainty of a long-term future, which she struggles to accept. Previously enjoyable activities also do not provide reassurance and in fact become a reminder of changes to her life as a result of cancer.</p> <ul style="list-style-type: none"> ✓ <i>Trying to find a balance between paid and unpaid activities in light of financial concerns</i> ✓ <i>Struggling to maintain the importance of her professional life in the context of a fragile future</i> ✓ <i>Having to select her activities be able to maintain fragile well-being</i> 	<p>Time 2: Adjusting her life to protect her well-being regardless of challenges</p> <p>Similarly to the first interview, Johanna tries to focus on the present to be able to cope with her situation. She also describes the emotional impact of having to deal with unpredictable bowel movements. These are not only a reminder of her situation but seem to be challenging in themselves as she finds them embarrassing. In the context of a poor prognosis, Johanna tries to enjoy the time she has by minimising the stressors in her life.</p> <ul style="list-style-type: none"> ✓ <i>Having to focus on the immediate future to be able to cope</i> ✓ <i>Experiencing emotional turmoil as a result of physical suffering</i> ✓ <i>Minimising stressors and enjoying life</i> 	<p>Time 2: Wanting people to join him in minimising the presence of cancer in his life</p> <p>Similarly to the first interview, George continues using his previously mentioned strategies of dealing with his situation. He realises the loss of long-term future which seems to motivate him to continue living the life he wants for as long as possible. He also hopes to be able to return to some of the activities following the end of the treatment.</p> <ul style="list-style-type: none"> ✓ <i>Experiencing a predictable routine of some deterioration and quick recovery</i> ✓ <i>Being determined to be in control of his life for as long as possible</i> ✓ <i>Being desperate to go back to previously enjoyed activities</i>

Participants experience different degrees of losses of their previous body and consequently quality of their day-to-day life. James, Chris, Linda and Kate experience ongoing physical suffering. For Chris and Linda, this is related to recovery from the surgery and associated bowel problems, while for James it is related to the ongoing chemotherapy regime and its side effects. Finally, for Kate the symptoms trigger a worry of another cancer recurrence. In contrast, Johanna and George seem to only experience intermittent physical symptoms, which as a result have less impact on their day-to-day life.

However, the meaning of this suffering is different for patients depending on their prognosis. While for patients with a poor prognosis, such as James and Johanna, experiencing side effects, either permanently or temporarily, is a direct reminder of their situation and the threat of death, not experiencing severe side effects despite a poor prognosis means for George that it is possible to regain one's previous life. Chris and, with time, Linda, who received a better prognosis yet are experiencing ongoing problems with their bowels, perceive the suffering as a sign of the recovery process from the surgery. In contrast, Kate is experiencing mild but ongoing symptoms which do not interfere with her day-to-day life, but nevertheless mean that she does not want to return to her previous day-to-day rhythm.

James and initially Linda experience severe side effects of treatment. They try to deal with the severe physical suffering, which for James is his ongoing chemotherapy regime and for Linda a slow recovery from the surgery. At the time of the first interview, we can see James' struggle to deal with the treatment regime. He has his treatment on a two-weekly basis and seems to experience the routine of the severe deterioration and slow recovery. He has to face a demanding treatment regime and his life seems to be divided into two weekly blocks of quick deterioration and slow recovery. He experiences severe side effects, which seem to make him question his ability to continue the treatment. Here James describes the few hours he experiences following the start of the chemotherapy. We can see the extent of the physical suffering he goes through in this period of time. This rapid change and inability to do anything almost means that he is no longer who he used to be. Instead, he almost becomes childlike, with the nurse "having the blanket ready":

Once the Ironotecan goes in I feel very ill instantly basically within about the 2-3 minutes of the Ironotecan going in. It is incredible really how ill it makes me. At that point, I say I go to sleep, but it is not really sleep. I kind of almost pass out until, and the nurse knows it, so she just, we just have the blanket ready and I go out and she just then connects the other drugs up without me even coming round [...]. And then I kind of wake up after that feeling dreadful and my wife comes to pick me up when I am ready.

This is, however, only the beginning of the slow process of the recovery with being discharged home starting this slow process. It does not actually involve returning to full strength but to the state which James defines as feeling “reasonably well”. We can see how in the process of the recovery, he starts to be able occupy more space and be part of the family as well:

When X [partner] picks me up on Tuesday, I go straight to bed [...]. Then, the Wednesday, I pretty much stay in the bedroom. I will get up, get dressed most times unless I am particularly ill but I will tend to sit in the bedroom, particularly if the children are at home. I usually start improving at about 2-3 o'clock in the afternoon on Sunday and that is that predictable, that rapid change over a course of the hours that I will go over a course of an hour. I will go from pretty dreadful to reasonably well.

The impact of physical suffering is considered by James in the context of treatment options available to him. While James balances the acceptance of death with hope for more time and potentially more treatment options, he also reflects on the impact of the treatment on his life. The relentless nature of the treatment takes a toll on him both physically and emotionally and makes him question how long he can actually take the suffering. Even though he wants to be offered surgery, he also realises the costs associated with another round of treatment:

I mean even if I could have a surgery, I do not know how I would be able to do it. I notice it is getting a lot harder, that the treatment is getting a lot harder for me as well.

These concerns are also visible in the account of his wife Victoria, who also seems to question the limits of her partner suffering. This seems to create

challenges in their relationship, as they both feel frustrated with the lack of solution and the impact of the treatment regime of their lives. By the time of the second interview, we can see the shift in James' approach to his treatment and its impact on his life. He demonstrates an extreme will to continue with treatment regardless of both emotional and physical costs. It seems that faced with his approaching death, his main focus is on prolonging life rather than on quality of life as in the first interview. Here James describes his experience of radiotherapy, following which he suffered from severe complications and had to be taken to A&E. He not only accepts that but also shows his willingness to endure suffering, which is highlighted by the use of "no problem at all" as he goes to say:

If I had known what did happen was going to happen I would still have done it, no problem at all.

He continues to demonstrate his will to live also when talking about potential future treatment options. We can see his determination in exploring all the possible options by searching the internet and ensuring that the clinician is aware of them. This may suggest his awareness of the quickly-changing field of cancer treatments and demonstrates his proactive role as a patient. Above all, it also highlights his attempts at exploring all the possible avenues and maximising his chances of survival. Even after suffering from severe post-treatment complications, he describes the conversation he had with the clinician. We can clearly see James' determination here. He wants to ensure that the clinician fully understands his position in terms of the treatment. His determination to do whatever possible is clearly visible in the use of words "anything" and "no matter how painful":

You can have different things. [...] In case it requires any clarification: if there is anything, no matter how painful, please tell me. I will probably do it.

While James seems to be focused on extending his life, his partner becomes more and more concerned with the impact of relentless treatment on her partner as well as her day-to-day life. Hope of being offered another operation as well as of having more time, clearly visible at the time of the first interview, are being replaced by different types of hopes. He

consciously acknowledges the transition as he is aware that his hopes have changed in the last few months. However, his acceptance of lack of treatment options and as a result, imminent death, are met with another obstacle when he realises that it is not possible to have a break from treatment like he hoped he would be able to have. Regardless of the demanding regime he has had to endure, he is not willing to stop the treatment and what is left is longing for a break:

All that was keeping me going was, having now accepted that I am not going to have another operation, and knowing I am not going to get better was that he was going to say you can have a break, god that would be great.

At the time of the first interview, Linda's physical suffering seems to be related to recovery from the surgery rather than to the ongoing chemotherapy regime, like was the case for James. In fact, she is lying on the bed during the interview. She seems to be focused on trying to regain her capable body but this is a slow process and she faces a number of challenges. We can see the impact of the slow recovery on Linda's quality of life. Although Linda is very keen to return to her activities, she needs to very closely monitor her abilities. While she wants to make the most of the intermittent moments of feeling stronger, she is quickly reminded of her limits and fragility. Similarly to James, the space she was previously able to occupy has shrunk, as she is not able to go far because of her physical limitations. The comparison between her pre-cancer and current situations demonstrates the extent of the limitations imposed on her life by recurrence. She is no longer able to be person she used to be, who, in this example, was very keen on walks and physical activity. The person she feels she is now is in striking contrast to that, which she finds challenging:

I: So in terms of day to day social activities, that since the recurrence, has it changed?

R: It had because I haven't been very far, we were sort of trying to go out and I was too grim. We did go to x, to the town, but I have to go in the car and I mean, until I was ill we were walking couple of miles every night when I was not working, I was keeping healthy and fit.

Linda's partner Anthony also reflects on these changes, which in turn bring feelings of loneliness, as they represent the loss of a partner he used to know. He describes his frustrations with caring for his partner and lack of hope for her improvement. In contrast, regardless of the challenges, Linda attempts to be positive about the recovery. We can see her determination to stay positive here and the belief that she is going to be better. She seems to see a positive attitude as facilitating recovery and only intermittently does she give herself permission to "mope" and "moan" at times of distress:

I always try to be very positive about things even though it's grim. I feel, I can't say for certain but I feel I am going to get better and that is also healing, your attitude because if you are constantly mooning and moping about things I mean, it is far better to be positive. I mean you can't always be and there are days when you feel very emotional about things.

Regardless of trying to stay positive and looking towards the future, the experience of a colostomy seems to be particularly difficult for Linda. We can see her efforts to adjust to that situation. While she was able to avoid a colostomy following the initial surgery, she has to face it for the recurrence. She reframes it as lifesaving to be able to manage the impact of it:

After the last one, he said he would have to do it because of the involvement of, whatever that is, I mean it is a means of surviving isn't it Marta after all, so hey ho.

Later on, we can see the full impact of the colostomy on her well-being though. Although she sees how she "got used to it", the impact is still presented as ongoing:

I can't bear the thought of that; it is such a horrible smell all the time. I am so bothered by it.

While for James his day-to-day life becomes focused on the ongoing deterioration and recovery from the chemotherapy, which only slightly allows him to be part of his previous day-to-day life, at the time of the second interview, Linda is feeling better and we can see some progress she has made both in her physical and as a result, emotional well-being.

What seems to be the main difference is her expectations towards herself and the way she manages her body. She seems to accept the limitations of her body and strength and adjust her routine accordingly. Here, Linda reflects on the changes to her energy levels by comparing how she is now and before cancer. The comparison also reveals not only the change in strength, but also how she manages the physical resources. Unlike before, she is willing to tune in with her body now and have a rest. The reason behind the loss of energy also seems to fuel the new approach:

Well, if I feel tired, I lay on a bed, which is something I have never done before. Before I was ill, If I was, well I would be busy all day and would be absolutely exhausted and I would sit on the sofa and watch the television but I would be up next morning but now I know when I have had enough. My body tells me that I am exhausted so go and lay down even if it is only 10 minutes.

Regardless of accepting the challenges and limitations of her new body, she also seems to embrace the recovery and is determined to go back to previous activities, almost wanting to prove to herself that she is able to do things. Related to that, we can see Linda's determination to regain her strength and the satisfaction it gives her. She seems to perceive the recovery as her responsibility and this drives her determination to recover. We can see the desire to reject the sick role and the limitations imposed on her when saying: *I don't want to be like this*. She contrasts the struggle she goes through to the easiness of the approach she could have taken. She seems to motivate herself regardless of challenges. Although she acknowledges the support from other people, she seems to see the ultimate responsibility with herself:

When I had this last major operation and I thought I should be lucky to walk again because that leg was like a tree trunk, you know, and X [partner] said we could get you some special shoes made and I am thinking: I don't want to be like this and I could have taken to the wheelchair easily because of the pain but you keep thinking come on, come one, you have to, you have to help yourself and it's not good everyone else expecting to help you because there is only certain amount others can do, yes?

Anthony also reflects on these positive changes, and his wife's slow return to day-to-day activities seems to bring hope. While Linda seems to describe how she now tries to monitor her abilities and modify her activities accordingly, Anthony also describes how this has had an impact on the running of the household. He tries to help Linda while also facilitating her recovery by allowing her to take on more chores. This enables their relationship to regain some normality.

Similarly to the initial interview, regardless of her attempts to remain positive and take charge of recovery, having a stoma seems to be one of the most challenging aspects. Here, Linda describes one of the examples where her stoma leaked while being on holiday. As she explains, it is not the fact that she has to have a stoma but rather the consequences of it not working that have a major impact on her quality of life. The severity of the distress Linda is facing is clearly visible in managing her stoma when trying to be part of normal life. She describes here the challenges she has to go through when going out and having to use public toilets to manage her stoma. The abnormality of the experience is revealed here when she describes it as a non-human:

I mean it is totally alien to what you are normally expected to do. I mean, if you want to want to go to the bathroom, you go to the bathroom, you are not supposed to kneel on the floor.

While James' and Linda's experience of physical suffering seems to be mainly related to recovery from treatment, Chris' experience of physical suffering seems to be related to experiencing severely unpredictable bowel movements. As a result of this, he suffers a number of losses to the quality of his day to day life, including social life and work. He is not able to continue working and we can see the distressing impact of lack of control over his bowel. The distressing nature is clearly visible here as challenging his dignity as well:

It is just totally impossible for me to work a normal working day because you cannot drive the taxi and have effectively a nappy full of poo and it is just not right, it can't be done and it is degrading and everything that goes with it.

Regardless of the challenges, he is envisaging the return to his previous activities. This requires careful planning around his bowel movements. However, similarly to Linda, we can see Chris' determination to return to his previous activities, including work. He challenges the clinician's doubts and wants to make the decision about returning to work when he "feels he can". This again is motivated by wanting to return to his previous life and being able to work seems to be an important part of his self-image:

From his [consultant] point of view, with the way how my bowels are, it would be unlikely to be able to return to my work in the normal full time capacity. However, I don't sit back and take things as gospel say. I will start working again as soon as I can feel I can. I want to do the things that I always done.

Envisaging a return to previous activities is clearly linked to Chris' attempts to regain control over his bowel movements. He follows a strict diet to be able to get through the day. Chris' partner supports him in dealing with day-to-day impact of having a stoma by making changes to her diet as well. Despite acknowledging some limitations to her life as a result of having to adopt this new diet, she seems to see these changes as her responsibility for the well-being of her partner.

Despite losing weight, he continues with this regime. While it allows him to return to some longed-for activities in the day, the strict regime has an impact on Chris in the evening and can result in extreme distress. By the time of the second interview, Chris has returned to work on a part-time basis. He has amended his diet further with giving up lunch to be able to have control over his bowels. Being able to go back to work is clearly important to Chris and has a two-fold benefit. Although Chris mentions the financial reasons, they are not described in detail at first, which may suggest that "peace of mind" is in fact the motivating factor for him. The desire to regain a "normal life" is visible here as well as he wants to be the person who he used to be:

I went back for two reasons, partly financial but partly for my own peace of mind. I need to have a normal life as best as possible and I am one of these people I need to be motivated. I can't, I am not very good at motivating myself at home doing the jobs around the house,

so if it is to Hoover, or watch the news on the telly I will probably watch the news on the telly. Whereas at work, I work, I probably won't make any more money but it is giving me a piece of mind.

The slow return to previously not achievable activities also has an impact on how Linda perceives her role in supporting her partner. At the second interview she reflects on the need to decrease the intensity of her support to facilitate her partner's independence, as maintaining previously established routines can now cause tensions in the relationship. Regardless of Chris' efforts, he is still not able to control his bowel movements all the time. While Chris follows the strict regime throughout the day to be able to control the bowel, he faces the consequences of that in the evening. Restricting bowel movements in the day means that he has to face disrupted sleep and numerous bowel movements in the night. This is also difficult physically and emotionally:

And then I would have an evening meal with my wife at about 5:30 and then my bowel movement can start from any time of 2 hours after that and it can be one or two bowel movements or it can be as many as 12 movements all night long, which is very distressing and very sore.

Regardless of all the challenges related to unpredictable bowel movements, Chris still prefers not to have a stoma, if not absolutely necessary. The choice seems to be fuelled by Chris' hopes and belief that he will be able to return to some of his previous activities and that having a stoma will prevent him from doing them. He also envisages a number of problems which he could face if he has a stoma, which seem to be more distressing than the current situation. Similarly to Linda, the only exception to his attitude towards having a stoma seems to be if it is in fact lifesaving:

I would like to go swimming and things like that. Now, I know that there is always a way around the problem and people with colostomy bag do go swimming but it must create an awful lot of problems so I would rather be, be the way I am but I would have to have control because that would be awful if I had a movement in the swimming pool with other people, they would have to close the swimming pool and everything, not good. I would prefer not to have

to go back on the bag if possible but of course, hey what is better to have a bag and live and not to have a bag and live.

Although Kate, similarly to Chris, also experiences ongoing symptoms, her symptoms have different meaning as they trigger worry about the possibility of another recurrence. As a result, at the time of the first interview, Kate's life seems to be dominated by worries about the future. This uncertainty seems to trigger a change in priorities and leaves her wanting to make the most of her time. While she tries to go back to her previous life, this is being challenged by the medicalised life style. The scans, which are at the moment every three months, trigger worry and concerns, as she is worried about the meaning of the symptoms she is experiencing. Life is divided into three-monthly blocks and she is being brought back by each scan into cancer reality:

With the bowel cancer I knew that I would have annual check-ups or scans and in between everything happening at the hospital and when I am going more about more of my daily life and I can, and like I say I can do things with the cancer group and I can switch off to me then, I am fine, but there nearer it comes to the scan and you know that you are going to get the results to see whether you are fine or not, I get very anxious. That is challenging in itself. What is more challenging after liver resection is that it is not annual, it is three monthly, so I just had a CT. In a three months' time I will have another CT, erm, so those anxious moments, it's like least 4 times a year.

As a result of recurrence, Kate describes a change in her approach to life. The time she has seems to be very precious to her and as a result, she rejects certain activities as a waste of time and tries to set new priorities. The uncertainty of her situation, also visible here, seems to fuel this. While the illness progression seems to be outside Kate's control, she wants to take control of the time she has and make it valuable to her. She seems to see time as a gift, as described by being "allowed" it:

There is a lot of rubbish on the television, lots of soaps, to me that is absolute rubbish now. I feel like I have better things to do in my life. I do not mind documentaries, but watching literally quite a lot of

rubbish on the television I feel like it is a waste of whatever I am allowed.

Michael, Kate's partner, also describes at length the changes to his wife's perspective on life priorities. One of the main areas of difficulty for Michael seems to be her exercise regime, which he regards as excessive and which means that they spend little time together. This seems to be a result of her decision rather than his and we can see his difficulty in accepting these changes. This seems to create tensions as they both struggle to reconcile their different needs in the relationship. However, he also comments on the positive changes to his partner, such as improved self-confidence which he seems to admire.

As a result of recurrence, Kate also faces a number of possible future losses. The unpredictability of the illness makes it difficult for her to have long-term plans, one of which being trips to her dream locations to take photographs. At the time of the second interview, even in the context of clear scans, Kate seems to struggle to find balance in her life. There seems to be a tension between Kate's new priorities and needs and the pressure to live her previous life. One of the key concerns seems to be related to the pressure of regaining financial stability. Following the initial diagnosis, Kate has actively supported a number of cancer charities. While she enjoys her work with charities, she also realises that she needs to find paid employment, which seems to be challenging for her. Comparing her previous and current situation seems to be particularly difficult, as it highlights the losses to her previous life:

Emotionally, all over the place very much at the moment, not all because of the cancer diagnosis, just, it would be nice to get back on to like an even keel, for my work to return to a level that's comfortable financially again. So I think I've taken, sort of taken a little bit of a step back, to take stock of my life, and it becomes a little bit of an eye opener when you realise what you have had, to what it's like now.

Even in the light of financial concerns and her desire to work in cancer services, the uncertainty of the future makes Kate doubt the value of re-training. The precious limited time she possibly faces magnifies her

concerns. The struggle to find enjoyment in life while also finding employment seems to be the main challenge for Kate. The realisation that she will need to invest substantial amount of time to be able to regain her previous status is difficult:

I don't know whether I've got the time- I'm on about long-term now, not hours in the day sort of thing, because I don't feel certain about my future. I don't know whether I've got that time ahead to retrain, so that I could work in cancer services or something in psychology or counselling.

Kate also faces a loss of the previous enjoyment from her lifelong passion. The activity which previously brought her joy and was a form of relaxation is now in fact a trigger of unwanted thoughts and memories. As a result, Kate seems to change her way of maintaining her well-being from enjoying solitude to keeping busy. This means that she also faces losses to how she now perceives herself as she is not able to be the person she used to, which is difficult to accept. In contrast, her partner seems to hope for her return to her lifetime passion, and possibly also the person she used to be. While Kate considered selling her photography equipment, he highlights his objection for it. This decision may suggest not only rejecting changes to the past, but may signify a need for the hope for the future.

Unlike James, Linda, Chris and Kate who are constantly reminded about their condition by their bodies, Johanna and George suffer from intermittent rather than ongoing side effects and as a result, can enjoy greater quality of life. However, they also need to find ways of dealing with the intermittent side effects in the context of their overall prognosis.

At the time of the first interview, Johanna, who has received a terminal diagnosis, tries to regain emotional balance following the news. It is a challenging process, and her fragile well-being is being disturbed mainly by physical difficulties. Johanna seems to engage in specific strategies to be able to cope with her diagnosis. This seems to be a balance between being aware of the significance of the situation and "switching off". This lessens the impact of the losses she is facing.

I switched myself off. It is not that I am denying the situation. I found the way to cope because I was having these thoughts that I will not

see my sons getting married, but now I try to block these thoughts, live for the moment.

We can see similar disengagement here in relation to pain. While she mentions her concerns, she also tries to block these anxieties by not thinking about it and preparing herself to face them when the moment comes:

I sort of buried my head but I am just trying not to think about it, I will think about it when I need to.

Johanna's partner Alan also reflects on the potential meaning of the diagnosis on his life. He describes his distress at being faced with the potential loss of his partner, which is in clear contrast to how he envisaged his life. However, he does not share this with Johanna and this may contribute to the emotional distance between them. Regardless of the strategies she uses, the problems with bowels she is experiencing seem to bring the threat of death and the significance of the diagnosis to the forefront. This seems to be in striking contrast to days when she does not suffer physically, which allow her to be part of normal life:

On some days it can affect me where I feel I can't do anything, so on those days I just rest. Other days I am pretty normal, I do [...] all the normal things which you would do if you did not have cancer; but you have good and bad days.

By the time of the second interview, Johanna continues with strategies to preserve her fragile emotional well-being. The negative impact of the uncertainty of the future in preserving normality is also visible here. Planning enjoyable activities long-term become in fact a painful reminder of her situation. Again, she seems to focus on the present to be able to cope with the magnitude of the situation she faces. The inability to have long-term plans and the uncertainty of the future seem to trigger the distress. As a result, she focuses on the present where time is safely divided into weekly blocks. Trying to engage fully with life and enjoy "the here and now" seems to be one of the strategies she uses to preserve her emotional well-being:

I don't like thinking about too much of future. I did say only the other day, I was talking about what plants we will have in the garden next

summer, and X [partner] said to me, oh that is good that you are thinking what you are going to do next summer sort of thing, and I then sort of thought, gosh I wonder if I will still be here next summer. Just sort of really take each week as it comes really, you know and try not to dwell too much on it cause that is when I sort of start getting upset really, I try not to think about it but is at the back of my mind and just getting on with enjoying the here and now really.

Johanna also seems to preserve her well-being by trying to minimise the stressors in her life. As a result, she makes a decision to give up work, which she has found stressful. Dealing with treatment and the diagnosis of recurrence does not seem to leave any resources for her to deal with additional stressors. As she elaborates, she also wants to enjoy the time she has left and this seems to fuel the decision as well. This does not mean giving up on keeping busy, but only using the time for the activities which bring her enjoyment:

I mean my job was very stressful to be honest, and in the hospital and I just didn't feel that whatever amount of time I got left I didn't want to be there. I just really try to keep busy, coping with the general life, sort of trying to keep busy.

At the time of the second interview, like at the time of the initial interview, Johanna's emotional suffering seems to be triggered by experiencing physical symptoms. Physical suffering seems to be a powerful reminder of her situation and the reminder that she is "not normal". The also seem to bring emotional distress:

It is only if I am feeling uncomfortable and in pain and that gets me down because that reminds me of what I have got. If I got no pain or discomfort or anything like that, I am normal, and I can just enjoy the day but my down days are usually because I am not feeling very good.

Johanna's partner also seems to mention his wife's good and bad days, with the latter being described as one when his partner is not able to participate in day-to-day activities. Once again, when describing these days he seem to focus on the immediate impact of them, for example having to

take on more responsibility, and seems to avoid thinking about the future and losses.

Johanna also reveals that she is suffering with unpredictable bowel movements and as a result, uses incontinence pads. While other symptoms trigger some distress, as described earlier, suffering from incontinence seems to particularly challenging for her, and in fact she describes it as the most challenging. Being young also seems to magnify the emotional impact of incontinence. While she describes the practicalities of dealing with incontinence, the psychological impact is revealed here. The incontinence associated with older age clearly clashes here with the image she has for herself and contributes to her suffering. Here, symptoms are no longer simply a reminder of the situation and her poor prognosis, but are also distressing in themselves:

The worst impact is which is terribly terribly embarrassing really is that I have not got the complete control of my bowel really so I have to wear the incontinence pads. I am not incontinent but I do have leakage if you like and all that and the other and that sort of gets me down really. It sort of, I have to learn to cope with really, and it is horrible side effect but that the way it is. [...] I was only using sanitary towel that woman would use but now I have the proper pads and oh god, why me? At the age of 55 why am I like this.

Similarly to Johanna, George seems to experience only mild physical symptoms as a result of ongoing chemotherapy. At the time of the first interview, we can see his determination to maintain his previous life regardless of the diagnosis of recurrence. He is able to continue with his activities almost uninterrupted. Unlike James who experiences a number of side effects, George experiences little change in his functioning, with loss of appetite being the only evidence of the side effects:

To be honest, it is not really affecting me. I mean, I am retired, I go out most days, and we go out most days. The only thing is that after the chemo for the first two days I don't feel quite right. I lose my appetite.

Regardless of the desire to continue with his previous life, we can see the losses to his previous life. Activities, which George used to be able to do and enjoy, are no longer possible, including travelling, gardening or work around the house:

I mean, I used to do a lot of swimming. I had not done any swimming. As you see, we have a big garden, and I haven't been able to do the gardening, like I used to.

At time of the second interview, similarly to the initial interview, George does not seem to suffer from many side effects following treatment. In fact, the treatment seems to set the rhythm of the week, where he fluctuates from feeling "very good" to feeling "tired a bit". While for James, the routine of going to receive chemotherapy signifies a start to the period of severe suffering, for George this becomes almost a non-significant part of the routine. The predictable nature of the process seems to also apply to the period of recovery, when George starts feeling "right as rain". In fact, similarly to Johanna, the lack of symptoms makes him feel as if he was not diagnosed with a recurrence:

I go up on the Monday, I have it and I feel really good, and the Tuesday I feel good, and then seems like the Wednesday, Thursday and Friday I start to feel a bit tired, and then on the Saturday I'm OK, and like today I'm OK. But funny thing, Saturday, right as rain, I mean today I feel great, you wouldn't think there was anything wrong with me at all, I feel alright.

Like at the initial interview, George is determined for cancer to be in the background of his thinking and life. We can see the limitations of that here, when George acknowledges the intermittent nature of the opportunity to still enjoy his life. As a result, he embraces life. Continuing with his activities and his determination comes to light here as well. The image of the person he compares himself to, is in striking contrast to his own approach. He not only rejects it but also seems to enjoy the intensity of life he chooses for himself. This may suggest that his desire to maintain his previous life is a reflection of his need to preserve his sense of self. By engaging with his activities he seems to actively reject the image of a sick person. This

seems to be important not only for how he perceives himself but also how others see him:

Funnily enough our friends were saying that, when they were down Saturday, that our friend's sister knows someone who's having exactly the same treatment as me, with this drug, with all this coming out, and she went down and saw her, and all she does all day is sit in a chair with a blanket round her, and does nothing, you've got to make the most of it, you cannot, I cannot sit here and mope and say, you know, how bad I feel, things can only get worse and stuff like that.

We can see how George sees the recurrence here. He seems to undermine the impact of recurrence on his life, and the intermittent periods of being in the hospital, together with deterioration following treatment, seem to be the only indication of the situation. In fact, he describes his recurrence as merely a problem:

Yeah, yeah, yeah, we go out, we meet up, we're going to meet our daughter tomorrow actually, we're going out for lunch, we meet her out tomorrow. Nothing has changed whatsoever, there's nothing, apart from me having this problem, you know, when I go in the hospital and stuff like that, but nothing has changed.

However, similarly to the initial interview, George is still unable to enjoy previously undertaken activities. While he waits for the clinician's decision, he is already making plans for the holidays. The urgency of this and the desire to go back to these activities are visible here:

The thing is, he [friend] doesn't go on holiday now because of me, I've said to him when I see X [clinician] in March, I'm going to say to him look, can I fly, and the first thing we want to do is do a cruise, a riverboat cruise, and you know, he's all in favour of that, I mean the minute I get like, X [clinician] says yes, you can go, I'll do that, but it has affected me, as I say, the holidays.

5.4.4 Part B- Discussion of the Cross Case Superordinate Longitudinal Theme 2: “Trying to negotiate *the place of cancer in one’s life*”

The Cross Case Longitudinal Superordinate Theme 2: “*Trying to negotiate the place of cancer in one’s life*” describes the impact cancer had on patients’ day-to-day life and the approach they took in dealing with that. I will describe the process of loss and recovery of previous body and its impact on the quality of life and future plans.

Experiencing physical symptoms as a result of the treatment had an impact on patients’ quality of life. The body they used to know was lost and they had to face a process of trying to regain it. For patients who underwent surgery the process was often long and included a number of stages, from being cared for to trying to return to previous activities. In the stage of the severe physical suffering, a focus on future improvement was used to facilitate well-being. Once some strength was regained, a focus on day-to-day activities seemed to work better. This was often achieved by monitoring one’s body in order to use its resources carefully. Ceasing activities when spotting warning signs was a useful strategy. Being able to carry out previously unachievable activities did not only bring improvements in quality of life but also provided participants with a feeling of satisfaction and signified regained mastery over life. Equally, some areas of their previous life even with time could not be enjoyed, or required careful planning as a consequence of a fragile body. A similar process of moving from disembodiment to managing embodied control was described in a recent prospective longitudinal study exploring experiences of patients following initial surgery for bowel cancer (Taylor et al., 2010). It meant a slowly shifting focus from achieving appropriate food intake and balancing rest and activity to being able to regain one’s previous life patterns. It seems that following surgery for recurrence patients followed to some extent a similar process to their recovery from initial surgery. However, while for patients who had surgery following initial diagnosis it meant recovery from the treatment and becoming a survivor, losing physical strength following the treatment for recurrence could also be a reminder of facing the threat of death.

In this context, changes to participants’ bodies also had an impact on day-to-day life. Seeing cancer recurrence as life transforming event brought a

number of changes to participants' lives. Wanting to make the most of the time remaining was seen as important but was not easy to achieve. The limitations imposed by cancer on the individual did not allow some of these dreams to be fulfilled. Patients' lives changed dramatically following the diagnosis of recurrence and their normal ways of being were challenged. They described losing previous rhythms of life, where undertaking previous activities was no longer possible. They were often no longer able to participate in the family, social and professional spheres of their life. Consequently, the way patients perceived their roles in families and wider social context also changed. These losses were often due to changes to their bodies, which could no longer be taken for granted. The life they once led and knew was no longer possible and they had to deal with numerous aspects of the uncertainty in relation to their lives, which in turn was unsettling. As a result, they often lacked opportunities to regain their emotional balance as cancer seemed to be present in all areas of their day-to-day life.

However, patients suffering physically as a consequence of the surgery were also focused on regaining overall physical strength and returning to their previous lives. However, in the context of a still-uncertain future, the value of decisions such as changing careers or returning to work was questioned. Activities such as work could lose their value as they were not perceived as meaningful anymore. While giving up work to enjoy life was potentially an option for older participants, for those outside retirement age it created feeling of being in limbo and in fact was often one of the main challenges they faced. While ceasing work meant a loss of income, it often also represented the loss of a previous life. The return to their previous lives meant different things for different participants. Some described the need to be able to participate in the family life, while others focused on returning to work. Participants seemed to perceive not being able to return to work or contribute to the household as more than just not being able to engage in their activities, but as a loss of their identity. This was especially visible when participants commented that they did not want to be the person who does not go to work or is able to cook a dinner for the family. In this context, these activities were no longer just part of day-to-day life but a reflection of the kind of person they were able and wanted to be. This feeling was perhaps magnified by their worries about how other might

perceive them as well: becoming less able. This paradox was also described in a study on relapsed myeloma where patients experienced a re-evaluation of their priorities, but because of the changing nature of the illness patients found that fulfilling their plans was often not possible (Maher & De Vries, 2011). Previous studies also revealed how previous lifestyle choices were questioned and led to a change in priorities. In the study by Coward and Wilkie (2010), patients described how they felt that a focus on work led in fact to recurrence and they were now committed to a less pressurised lifestyle. In other studies, thinking carefully how to make the most of the allowed time was also a focus for patients (Chunlestskul et al., 2008a, Ekwall et al., 2014).

Problems with bowel movements, as a particular example of moving between periods of recovery and deterioration, were also difficult to accept, and had major impact on day-to-day life for patients both with and without a stoma. This did not seem to change with time. A carefully selected diet to minimise the impact of bowel movements on their life did not always bring the needed results. This was challenging and made the illness seem unpredictable and magnified the feeling of loss of control over the situation. Having to carefully plan their activities provided a way to be part of their previous life. Similarly, for one patient in this study who had a stoma following recurrence, there was a difficulty in coming to terms with having it. Trying to reframe it as lifesaving did not always bring acceptance, as the perceived loss of dignity in managing the stoma seemed like a bigger sacrifice. Being determined not to have a stoma also suggests that a stoma is still perceived as significantly impacting on quality of life even by patients who did not have it. This is in line with previous research, which looked at the impact of bowel problems in patients with primary bowel cancer (Taylor et al., 2010). It was suggested that the feeling of disembodiment can initially facilitate psychological well-being as it protects the individual from the traumatic experiences of treatment. However, the individual needs to restore control and feeling toward one's body to be able to recover (Taylor, 2010). It seems that for patients with difficulty with bowel problems, the disconnection with their bodies continued for a long time.

However, in the current study the process of deterioration and recovery, especially for patients on a chemotherapy regime, was fluctuating rather than linear. In this context, regaining bodily control was not always

possible. In fact, body recovery and deterioration seem to dictate patients' ability to participate in their day-to-day lives. It meant losing the ability to participate in their previous life in the periods of deterioration, and slowly returning to activities in the periods of recovery. For patients who did not suffer from major side effects as part of the ongoing treatment, intermittent periods of deterioration were almost the only reminder of the severity of their situation and these in turn triggered emotional suffering. These difficulties in balancing periods of body deterioration and recovery were also found in a study in patients with recurrent ovarian cancer, where monitoring one's body was a way of knowing about possible disease progression as well as the limits to one's suffering. It also helped to maximise one's strength and make the best use of the good health periods (Ekwall et al., 2014). A study with metastatic breast cancer patients also described what they called the health status paradox: the sense that experiencing physical suffering was a reminder of death, which also triggered worries about death, while periods of being symptom-free facilitated the will to live.

Patients with a poor prognosis who were not suffering from side effects tried to focus on maintaining their previous rhythms of life. However, intermittent problems in the context of a poor prognosis were perceived by them in a different light. Filling their days with activities was one way of distraction from the reality of cancer, whereas envisaging potential future losses when faced with the possibility of death was distressing and in these instances, facilitated a focus on the present. Taking one day at a time and making the most of the time remaining became a way of coping. Previous studies have highlighted how thinking about the future caused distress, as it reminded patients about the losses (Ekwall et al., 2007, Chunleestkul et al., 2008a). Similarly, focusing on the present enabled coping as it lessened worries about the disease progression (Griffiths et al., 2008). On the other hand, it often inhibited having short-term as well as long-term future planning as patients found themselves able to plan neither holidays nor retirement (Maher & De Vries, 2011).

5.4.5 Part A- Cross Case Superordinate Longitudinal Theme 3: *“Sharing and not sharing the experience of recurrence”*

As described in Theme 2: “Trying to negotiate the place of cancer in one’s life”, the diagnosis of recurrence had a significant impact on participants lives. However, the extent to which this impact is shared with other people varies as the diagnosis of recurrence is negotiated in a wider context of families, friends and communities. Participants vary in the extent to which their and their family’s needs in relation to sharing are convergent with each other. The theme of “Sharing and not sharing the experience of recurrence” describes this aspect of their illness experience.

Discussing the diagnosis of recurrence and its potential consequences is one way, perhaps the most explicit one, of sharing and not sharing the experiences of illness with people. These discussions are focused on a number of areas including the feelings evoked by the cancer diagnosis, information about their illness, as well as the present and future consequences of the diagnosis of recurrence such as preparing for death. While some participants want to discuss the diagnosis of recurrence with their families, others do not instigate these conversations with people. This issue is quite complex as participants can also experience different degrees of sharing with different people, as they disclose and discuss certain aspects of their illness experience with some people, while not others. Regardless of these challenges, it seems that finding a person to share these feelings with, even intermittently, is important for participants and some seek support outside their families to be able to fulfil this need.

The other aspect of sharing and not sharing is related to the potential discrepancy between participants’ and other people’s perception of what day-to-day life should look like. While some participants are willing and accepting of the need to reduce or change their usual activities and receive practical support from their families, others struggle with this. While for patients who are physically not able to help their families this is related to the feeling of being a burden, for patients who are recovering this is mainly related to rejecting the label of a “cancer patient”.

These two aspects are intertwined in participants’ accounts, with the extent of discrepancy between participants’ and other people’s willingness to discuss the diagnosis having an impact on the way day-to-day life should

look. In this context, not discussing the diagnosis can mean rejecting the label of “cancer patient”, or in fact living a pre-cancer life because of a lack of opportunities to discuss the diagnosis.

As previously described in the Methodology chapter, Table 5.4.5 sets out the Cross Case Longitudinal Superordinate Theme 3 and then, for each patient, their individual within case Longitudinal Superordinate Theme, together with their individual Superordinate Theme at Time 1 and at Time 2, and Subordinate themes identified.

Table 5.4.5 Cross Case Longitudinal Superordinate Theme 3: Sharing and not sharing the experience of recurrence

Cross Case Longitudinal Superordinate Theme 3: Sharing and not sharing the experience of recurrence		
<p>James: Going towards death together and alone</p> <p>Time 1: Sharing and not sharing the burden of cancer</p> <p>At the time of the first interview, James describes his struggles with his feeling of being a burden, as he is no longer able to participate in the day-to-day life of his family. Together with his partner, he tries to minimise the disruption to their children’s lives while the emotional impact of his diagnosis becomes a taboo subject between them.</p> <ul style="list-style-type: none"> ✓ <i>Coming to terms with feeling a burden</i> ✓ <i>Attempting to minimise the disruption to children’s lives</i> 	<p>Johanna: Balancing family silence against support from cancer community in approaching death</p> <p>Time 1: Drifting from family in sharing the meaning of diagnosis</p> <p>At the time of the first interview, Johanna describes how following the news, she and her partner started to grow apart. She seems to perceive his partner’s interpretation of the situation as overoptimistic, which in turn prevents them from talking about the severity of her situation. However, she seems to find support in cancer groups.</p> <ul style="list-style-type: none"> ✓ <i>Pulling apart because of unshared feelings after “good news”.</i> ✓ <i>Sharing the experience of cancer facilitating understanding and empathy</i> 	<p>George: Wanting people to join him in living previous life</p> <p>Time 1: Balancing the maintenance of family routine with changes following his death</p> <p>At the time of the first interview, George wants his family to join him in living his previous life. He rejects the sick role in the family and wants to be treated in the same way as before the diagnosis of cancer.</p> <ul style="list-style-type: none"> ✓ <i>Envisaging the changes to family life after his death</i> ✓ <i>Minimising impact of cancer on his life in the family context</i>

Table 5.4.5 Continued Cross Case Longitudinal Superordinate Theme 3: Sharing and not sharing the experience of recurrence

Cross Case Longitudinal Superordinate Theme 3: Sharing and not sharing the experience of recurrence		
<p>Time 2: Facing imminent death together and alone</p> <p>Over the course of time since the first interview, difficulties in talking about the severity of his situation with his partner become magnified, with the topic of death becoming absent from any conversations. In the context of these difficulties, he tries to minimise the feeling of being a burden on his own, by sorting out his financial affairs.</p> <ul style="list-style-type: none"> ✓ <i>Managing the burden on the family</i> ✓ <i>Attempting to warn children about his death</i> ✓ <i>Getting ready for death on his own</i> 	<p>Time 2: Facing her death preparations outside of her family</p> <p>At the time of the second interview, Johanna describes her ongoing difficulties in talking to her family about her situation and her potentially approaching death. She continues to use cancer support groups as a platform for sharing her worries and feelings.</p> <ul style="list-style-type: none"> ✓ <i>Facing preparations for death on her own</i> ✓ <i>Locating support in a cancer community of “strangers”</i> 	<p>Time 2: Wanting people to join him in minimising the presence of cancer in his life</p> <p>Similarly to the first interview, George continues with his strategy of minimising the presence of cancer in his family life. This approach also extends beyond the family as he carefully chooses people to talk about his situation while rejecting a need for formal support.</p> <ul style="list-style-type: none"> ✓ <i>Being determined to leave cancer out of family life</i> ✓ <i>Avoiding talking about cancer to maintain emotional balance</i> ✓ <i>Carefully selecting a network to talk to</i>

Table 5.4.5 Continued Cross Case Longitudinal Superordinate Theme 3: Sharing and not sharing the experience of recurrence

Cross Case Longitudinal Superordinate Theme 3: Sharing and not sharing the experience of recurrence		
<p>Kate: Balancing new and old roles in the family context</p> <p>Time 1: Recurrence-triggered transformations of self, causing family difficulties</p> <p>At the time of the first interview, Kate talks at length about the difficulties in sharing her experience of recurrence with her family. She feels that her family tries to impose a sick role on her, which she tries to reject. As a result of her difficulties, she locates her trust in nurses.</p> <ul style="list-style-type: none"> ✓ <i>Finding a safe haven in nurses</i> ✓ <i>Establishing a more confident self in family causing friction</i> ✓ <i>Taking on a new self in relationship with partner</i> 	<p>Linda: Managing the return of a capable self in the family context</p> <p>Time 1: Sharing the burden of recurrence with family following the diagnosis</p> <p>At the time of the first interview, Louise describes how slow recovery from the surgery prevents her from being able to contribute to her family day-to-day life. In addition to her own struggles to accept her limitations, she also needs to deal with her partner's feeling of hopelessness.</p> <ul style="list-style-type: none"> ✓ <i>Losing pre-cancer roles causing distress</i> ✓ <i>Dealing with partner's feelings of hopelessness</i> 	<p>Chris: Balancing private and public experiences of recurrence</p> <p>Time 1: Managing the threat of cancer privately and in public</p> <p>At the time of the first interview, Chris describes his initial reservations about talking to people about his situation. This changes with time and helps him to cope with the situation. He also appreciates support from family. Despite his willingness to discuss his diagnosis, some aspects of his illness are shared only with a partner.</p> <ul style="list-style-type: none"> ✓ <i>Making his diagnosis public to help himself and other people</i> ✓ <i>Wanting and valuing genuine support</i> ✓ <i>Not being able to be part of his previous life because of bowel problems</i>

Table 5.4.5 Continued Cross Case Longitudinal Superordinate Theme 3: Sharing and not sharing the experience of recurrence

Cross Case Longitudinal Superordinate Theme 3: Sharing and not sharing the experience of recurrence		
<p>Time 2: Trying to make sense of her new needs</p> <p>By the time of the second interview, Kate does not seem to seek the support from nurses as frequently as before. She continues to struggle to establish a new dynamic in her family as she oscillates between wanting to fulfil her new needs and feeling guilty about doing so.</p> <ul style="list-style-type: none"> ✓ <i>Leaving the support from nurses behind</i> ✓ <i>Experiencing different relationships with family following diagnosis</i> ✓ <i>Struggling to manage her and her family's needs</i> 	<p>Time 2: Wanting family to embrace her recovery regardless of challenges</p> <p>By the time of the second interview, Linda's physical strength improved and as a result, so did her ability to return to her previous activities. As a result, she wants her family to respond to her changing needs and provide more balanced support, which proves to be difficult.</p> <ul style="list-style-type: none"> ✓ <i>Wanting people to allow her to go back to previous life</i> ✓ <i>Valuing partner's support in severe distress</i> ✓ <i>Appreciating ongoing support from people while not seeing the need for it</i> 	<p>Time 2: Sharing the experience of recovery with people privately and in public</p> <p>By the time of the second interview, Chris' initial reservations about talking about his experience of recurrence are gone as he continues to benefit from sharing. He perceives his experiences of cancer as a joint effort with his family, which he appreciates. He also reflects on his ongoing struggles in sharing certain aspects of his illness with others.</p> <ul style="list-style-type: none"> ✓ <i>Sharing his experience of recovery</i> ✓ <i>Seeing the experience of cancer as a joint effort with his family</i> ✓ <i>Having to find people ready to share his challenges</i>

James, Johanna and George have all received a poorer prognosis and as a result are aware of the lack of hope for cure. For James and Johanna, this seems to influence their willingness to start conversations with their families about the possibility of death and more importantly, the extent of these conversations with their families. Their situation also has an impact on how their day-to-day living is shared with people. In contrast, receiving a terminal prognosis results in a different approach for George, who chooses to maintain his pre-cancer life and wishes for his family to join him in this approach.

Kate and Linda also seem to experience some discrepancies between their and their family's needs. Although fears around the potential threat to their lives are present, as they both undergo surgery, with time the focus seems to shift from the issues around facing mortality to recovery. In contrast to these participants, Chris seems to perceive the experience of recurrence as a joint endeavour with his family, whom he feels support him through this difficult time, while facing some challenges in sharing his day-to-day life with people outside the family.

Both James and Johanna seem to experience difficulty in talking about their diagnosis and its potential as well as its real meaning with their partners and children. We can see their need to discuss the issues related to their diagnosis and its consequences including preparations for their funerals. The difficulties in having these conversations seem to continue and in fact, to some extent increase over time, with approaching death becoming a taboo subject. For James, we can see also the additional difficulty in sharing his day-to-day life, given his limited physical strength.

In his first interview, James describes at length the difficulty in discussing the diagnosis and its meaning with his partner. His concerns about the consequences of his death are shared with his spouse but only to a certain extent, due to her reluctance to talk about it:

You have psychological problems of children not having a father. We talk about it, but sometimes she [partner] does not want to talk about it.

This difficulty in sharing the understanding and its emotional impact does not only apply to his relationship with his partner but is also visible in his

relationship with his children. Only some aspects of the experience are shared with his children, while some remain protected: while his children can see the suffering they are not aware of the meaning behind it. James' partner Victoria seems to share this approach, while also worrying about the extent to which children are aware of the situation. She also highlights the need to maintain some normality for children by continuing with daily activities. In addition to difficulties in sharing the feelings related to the situation, James also describes the difficulty of sharing day-to-day life with his family. Throughout the whole first interview, James describes the impact of the diagnosis and illness on his partner and family and his feelings of being a burden. We can see that not only he is not able to contribute to the household as he was previously, but he also feels that he adds to the burden by being dependent on his partner's support. By listing the items of support he requires from his partner, we can see the extent of the impact of cancer recurrence on both James and his partner's lives. The preparation of snacks as an activity demanding little energy from a healthy individual highlights how even little things have become problematic for James and how he has to delegate them to his partner. He seems to realise his dependency on his spouse and we can see how this dependency on her resembles the dependency of the child on an adult:

She can't rely on me for things that I used to do around the house. [...] There are times where she has to do things for me as well, kind of take me to and from the hospital, cook me meals, cause I can't even do things like that sometimes you know, prepare me even snacks sometimes.

Victoria also talks at length about the impact of treatment on her partner. While she struggles with witnessing her partner's suffering, she also describes her frustrations. These are mainly related to her partner not being able to support her in running the household and a feeling of having to take a responsibility for everyone.

At the time of the second interview, both James and his partner continually negotiate the painful reality of his illness. While initially we could see James' attempts at starting conversations about his death, here we can see the shift in his approach. He seems to accept his partner's difficulty in talking about the situation. Instead, cancer and his approaching death are

spoken about implicitly by “making reference” to them. It seems to be a strategy of managing the painful impact of his situation. Talking about it becomes irrelevant as “they both know what that means”:

I tend not to speak to X [partner] about it. She gets so upset, all it does it upsets her. She does not like it basically. We occasionally make a reference to it, in terms of planning of the holidays, maybe the last time we go kind of thing was said during the course of planning cause we both know what that means.

This change of approach also seems to be visible in the relationship with his children. While initially he describes how his children seeing his suffering gives them some indication of his situation, here we can see that these preparations also are leading to a final truth that “he is not going to get better”. The ongoing exposure to his cancer is in fact a preparation for the time of his death:

They know that daddy is unwell, we tell them daddy is not well. We have not told them that daddy is going to die. We have taken the oldest to the hospital to pick me. [...] We decided that when daddy becomes more ill, that we then, they are prepared for it by the virtue of the fact that they have known all the time that daddy has been ill and that is that point that we decided that we will tell them that daddy is not going to get better.

At the time of the second interview, we can see how James continues to struggle with the limitations imposed by his illness on his day-to-day life and how these are negotiated in the context of his approaching death. He talks at length about sorting out his financial affairs and the repetition of “everything” in relation to his financial affairs may suggest his acceptance of an irreversible future. This is also evident when he envisages his partner’s future without him. We can see the importance of this situation to James in the way he highlights the fact that it is the first time that he doesn’t have a bank account. The way this passage unfolds lets us see the emotional impact of this on the superficially unemotional preparations. Lessening the practical burden on his partner is in fact one way of showing that he cares about his family and becomes one of the key ways of his showing love for them:

Everything is in X 's [partner] name, I don't have the bank account any more for the first time, I don't have a single financial, everything is either in X's [partner] name or joint names, so once I am not here she can access it without [...] having the whole hassle. That is me being organised again, because you just care about your family so much [cries]. So I say I have done everything.

In contrast, James' partner Victoria does not talk about the financial affairs, which might reflect James' rather than her need to sort financial affairs. She seems to focus on the present and further decline of her partner's physical strength and its impact on her daily life. It might be that she is unable to engage with the future losses to her life yet. This creates difficulty for James as he feels unable to talk to her about the future after he is gone.

Similarly to James, Johanna has been receiving chemotherapy to control her cancer and was told initially about the poor prognosis following recurrence. She also describes the difficulties of facing the potential meaning of the diagnosis of recurrence with her partner. At the time of the first interview, Johanna talks at length about the delivery of the news and its impact. The despair of the news was initially shared with her partner as they seemed to be brought closer by sharing feelings and "crying together". The use of "we" when describing the reaction is evident here, as she explains here:

[Consultant] was absolutely blunt. We sort of left feeling that there was no hope and my husband and I just went home and cried.

She goes on to describe how, soon after that, the understanding of the situation is no longer shared between herself and her partner. When she is told by the clinician that the cancer has not progressed further following the first dose of chemotherapy, her husband seems to hold on to the positive aspect of the news, which is not shared by Johanna. The emerging disparity between her and her partner's feelings seems to be contributing to her emotional suffering. We can see the change in the language used as well when initially the feelings are shared and how with time, they are diverging:

We just cried initially, he was in the same state. But when we got better news he was absolutely overjoyed, he was elated. I was not elated and I had very weepy days after that.

In Johanna's partner account, we can see how he tries to avoid addressing the overall severity of the situation. Instead, he seems to hold on to the recent good news about chemotherapy being effective in reducing the tumour. This inability to share worries and concerns seems also to be visible in her relationships with her children. Although unlike in James' case, her children are both adults, she experiences similar difficulties to him insofar that she is not able to discuss the reality of the situation with her them. In fact, she is encouraged by one of them to stay positive, while with her other son, cancer becomes a taboo subject, never mentioned or spoken about. Johanna's partner does not seem to share this concern and instead focuses on the ability of one of their sons to come home on a regular basis following the news. This means that Johanna is not able to discuss her feelings and her view of the situation with the family.

In the context of the difficulties of discussing her situation with her family, Johanna finds online cancer support groups as a platform to talk about her experiences. It seems that for Johanna, having a diagnosis of cancer in common with other cancer patients, brings them together and facilitates sharing of experiences. She seems to perceive sharing the diagnosis of cancer as sharing the same feelings and concerns. This sameness allows the sharing of severe distress, which people without cancer may not be able to respond to. The perception that sharing the diagnosis of cancer means sharing the same feelings and concerns may in fact be magnified by the lack of understanding of her family, where not having cancer is a barrier which does not allow connecting:

Cause they do not understand [family], do they, they have not had cancer, they are not going through the same I am going through.

Johanna's partner, Alan, also highlights the benefits of her belonging to different groups. He seems to be pleased that she received this support and also highlights the similarity in his partner's and other people's experiences as key when providing support. His approach might be a result of his difficulties in talking about the emotional impact of his partner's diagnosis in general. At the time of the second interview, Johanna talks about her continuing difficulties in sharing her feelings with her family. The loneliness of this aspect of her experience is also visible in her thinking about her funeral, when, similarly to James, she describes the inability to

talk to her partner about it. She nevertheless thinks about these issues on her own and carefully considers other family members she could share these conversations and consequently, preparations with:

Obviously things like what I would like for my funeral and I could not ever, never discuss that with X [partner] he would get too upset about that so I mull it over in my head in you like. And that might be something which I will discuss something with my sister because it will upset him.

In the light of this, she seems to get involved with even more online cancer groups. She describes a number of benefits of being part of these groups and the sense of belonging which it brings. We can see how the “strangers” from online communities become friends and the value of support they bring is perceived by Johanna:

They are all very supportive and they, it is good for me. I know it is not everyone cup of tea to chat away to strangers and all that and the other but it has been great for me. I enjoyed it to be honest, they become as I say very good friends to me, friends that I have never met but they are always there with support and advice.

In contrast to these two participants is George. While similarly to James and Johanna he also does not share the emotional impact of the diagnosis of recurrence with his family, this approach seems to be instigated mainly by himself. Throughout both interviews he describes the minimal impact the diagnosis of recurrence has on both his emotions and his life and he wants his family to join him in the same approach. This decision seems to be to a certain extent fuelled by the fact that he has been suffering from few side effects following his chemotherapy regime, which have allowed him to hold on to the rhythm of his pre-cancer life. While he talks at length about the minimal impact of cancer on his life, there is an indication that this approach is not shared by his wife:

Well, she worries more, whereas I don't worry so much whereas my wife worries about it.

This approach seems to continue for George and at the time of the second interview, cancer still seems to be almost non-existent entity in George's

family life. Not wanting to talk about the experience seems to be an important way of maintaining emotional balance as talking could be a reminder of the situation. George seems to differentiate between sharing as letting people know what the situation is, and talking about his feelings. While he is happy to do the former as he perceives telling the family about the recurrence as sufficient, he does not seem to welcome the emotional sharing:

Q: So kind of do you ever talk about cancer with your family then?

R: well, no, not really, they know the situation, they all know the situation, all of them [...]. They all know exactly what's happened, right from day one we've told them the situation, I haven't tried to cover anything up. At the same time I don't want anything, I don't want any special concessions at all. I mean I tell people, you know, friends, they all know the situation, I don't want them, you know, phoning up and saying how are you, you feeling any better and all that, they just treat me as normal.

George rejects the sick role in the family and wants to be treated in the same way as before he had cancer. This seems to be very important to George as highlighted by a repetition of wanting to be treated “normal”, leading “normal” life and “going on as normal”:

I just want them to treat me as normal, how I was before I had this problem, I just want to go on just as normal, I don't want any concessions at all, you know, I just want to go on as normal, live like a normal life as much as possible.

Similarly to Johanna, George also seems to carefully select the network to talk to. While at the time of the first interview, he does not mention any attempts to seek support either within the family or outside it, at the time of the second interview he presents the rationale for not seeking formal support, such as through cancer support groups. Unlike Johanna, he rejects the support group as another reminder of his situation. Belonging to such a group is perceived as a very visible acknowledgement of being a cancer patient, the identity of which he rejects:

If I start going to these places for support and stuff like that I think it'll just make, it'll make it worse, I just want to go on with my life. I know things aren't going to be all that good later on, but I've just got to get on with my life, I can't let it get me down, and I'm sure if I started going to these charities and stuff like that, looking for support, it'll make me feel worse.

He seems to reject the idea of formal support and sees “chatting” to a friend as valuable. However, even talking to a friend is carefully constructed as a chat only and not a support:

R: I mean I've talked to people that's got it, I mean this friend of mine that's got it, I've had a chat to him.

I: So you like support each other?

R: well we talk about it. [...] When, when we meet or just say, you know, how's your treatment going, and when he was in hospital last time we went up and saw him, we just talk about it.

As we have seen, James, Johanna and George experience a discrepancy between their and their family's needs in sharing their illness experience. Given their poor prognosis, this discrepancy is mainly in relation to discussing the potential consequences of recurrence, such as preparations for death. We can see the loneliness of James and Johanna when they seem to engage in their preparations mainly on their own. In contrast, George's approach in not discussing cancer seems to be very important to him and he wants his family to join him in this approach, thus also suggesting a discrepancy between his and his family's needs. Although fears around the potential threat to their lives are also present for Kate and Linda, with time the focus seems to shift from the issues around facing mortality to recovery. This does not mean that these changes are easy for them and we can see challenges of negotiating new roles within the family.

Kate's experiences seem to be unique in showing the changes to her life post- cancer and how these are negotiated within the family. At the time of the first interview, Kate talks about the lack of support from her family, with her partner being an exception, and the difficulties of talking to her family about her experience. However, she also seems to introduce different degrees of sharing with her partner: while she is happy to talk about her

experiences to her partner, as indicated by “we discuss a lot”, there are things which become not shareable. Discussing her mortality and its impact on her husband seems to be one of these topics. This difficulty does not seem to be related to her partner’s unwillingness to discuss these feelings but, similarly to George, seems to be fuelled by Kate’s approach:

Cause I did not want to put everything, all of my feeling, my husband and I, we discuss a lot, we talk a lot to each other, but there were also things that worried me, I was also worried about his future, if things got to the point that I did not have a long-term future so the only people who I could turn to were health care professionals.

In the context of these difficulties, similarly to Johanna and George, Kate describes the valuable support she gains from outside her family, in her case from health care professionals. She reflects here how maybe her unusual family experiences may have impacted the way she has formed the relationship with her clinical team. The emotional void, similar to that described by Johanna, is clearly filled by the nurses. This makes it difficult for her to “break away” from the health care system, which seems to provide a safety net:

There is a lot of people who knock X [name] hospital but in my experience, I don’t know whether it is because I have such a weird family, in the, they do not show feelings, to me, they don’t show feelings and all of a sudden you are in the environment where they show you a lot of care and they want to look after you and make you better, it is very difficult breaking away.

Kate describes how cancer and more recently cancer recurrence has changed the way she sees herself and the way she interacts with family members. In this extract, she talks about the difficult relationship which she has with her family, who want to “wrap her in the cotton wool”. We can see the discrepancy between her need to be active and the family expectations for her to take on a sick role. We can see some similarity here with George as the sick role is perceived by Kate as old-fashioned and as such, she rejects it:

But everybody or a few people that are around me their attitude is that they do not want me to do anything, they want to treat me with the kid's gloves, wrap me in the cotton wool and I do not want that.

These changes are also evident in her relationship with her partner, although expressed in a slightly different form, probably because of the different nature of the relationship. The discrepancy between her and her partner's needs, although expressed, is presented in a more conservative manner. We can see how she cautiously contrasts her needs with her partner's needs. As she continues, she ascribes the difficulties they are facing to his lack of understanding, but quickly moves on from this interpretation and sees this more as a difficulty in acceptance. We can also see some of Kate's struggles to deal with those changes as she seems to be providing me with an explanation for her choice, namely it being a coping strategy:

He is not the most, he likes a bit of a stroll along the sea front as a walk, I want a lot more out of the physical exercise and that so it has now came the time that he is at home more on his own now and I am trying to get back to the exercise. So we are apart more than we have ever been and that it is, it caused problems in our marriage. Because he can't understand why I want, I think he can understand, but I think that he finds it difficult to accept that I need to do this. That is how I, it is like a coping strategy I suppose.

This is also reflected in the account of her partner, who worries about her well-being and the substantial amount of time she spends doing exercise. However, Michael acknowledges how Kate's new approach to life also challenges his previous image of cancer when minimising the activity was the only way of facing the diagnosis of cancer. At the time of the second interview, we can see some changes in Kate's relationships with health care professionals and some consolidating changes in the relationship with her family. Kate seems to still need some support from her Clinical Nurse Specialist, but she sees the decreasing need for that as she does not initiate contact herself. It seems that she has found new ways of coping, mainly by keeping busy, which replaces the need for support from the nurse:

My main support is CNS but I don't seem to be, I haven't contacted her for support. I think there's been times when, when I've wanted to, not, not regular, I did go through a spell where I needed a lot of hand holding to get through different times, but it, I don't know, I feel like I've, I've just thrown myself into so much, if I felt I want that, it's not very often that I need that.

While Kate's account seems to suggest a decreasing need for support, Michael seems to worry about the emotional well-being of his partner. In his interview, he describes instances when he calls the CNS for advice about ways of addressing the emotional needs of his partner.

Kate also seems to continue to negotiate the changes to self in the family context. She describes here how the previous way of communicating between herself and her mother has disappeared, and more importantly, how a new way of communicating has not yet been established. Kate's transformation to a self which she describes as "being more positive" does not seem to be accepted by her mother. Related to this, we can see Kate's struggles in her relationship with her partner. While at the first interview we seem to see more of Kate's reflections on the impact of her change of self on her partner, and some indication of guilt, by the time of the second interview, these dilemmas seem to be intensified. This lack of resolution is evident here. Kate reflects here about the overall impact of cancer on herself and we can see the two sides to her which she struggles to reconcile: the selfish self and the stronger self. The strength of that struggle is evident when Kate talks how things, which she "loves", she also "doesn't like". She seems to be imposing expectations on herself of how she "should" be and how she "wants" to be. She uses the cancer as a reason for this change and describes how previous ways of coping would have not worked in this situation:

R: I think if anything it's made me a stronger person. Some of it, some of it's for the better, like I said, the selfish side of me, because I like, you know, I like to throw myself into doing stuff I love now, I don't like that, I wish I could be, have a little bit more consideration for others.

Q: in what sense?

R: well family life really, should be a bit more thoughtful, but at the same time, if I was to spend perhaps the kind of hours at home like I used to before cancer, I wouldn't cope as well.

Linda, who was offered surgery, shares some similarities with George and Kate in wanting to return to her life and rejecting with time the role of being a sick person, which she seems to negotiate carefully in the family environment. At the time of the first interview, Linda talks about the loss of her role in her household and the impact of this loss on her. Slowly recovering from cancer treatment means for Linda that she is not able to contribute to the household and this in turn affects her feeling of self-worth:

It is just this feeling of, not being worthy but not being very useful, does that make sense? Because you are not able to help the family.

She also reflects on the impact of recurrence on her partner. While we see the frustration of Linda who seems to struggle to accept the imbalance in the family, she also talks about her partner's difficulties in accepting an inability to make things better. These difficulties are also clearly visible in her partner Anthony's interview:

My husband is excellent, I mean he is trying his hardest to please me and always does but I think I make him frustrated because he wants me to eat and get better.

By the time of the second interview, Linda seems to be regaining her strength and this change is also reflected in the family dynamics. Linda seems to get frustrated with her partner who seems to closely monitor her well-being. Although she acknowledges the fact that she has good and bad days, she sees it as unnecessary worry on her partner's part:

I mean he looks at me sometimes and he will say are you all right, are you ok, and I will say stop it, stop it, if I am not feeling very brilliant but as I said some days are good and some days are bad.

The dynamics of the recovery seem to be different for Linda and her family. These challenges might be more magnified than for Kate, who recovered well from the surgery and was able to re-join, or in fact start establishing a new rhythm for her life more quickly. Here, Linda reflects on the challenges

of slowly rejecting the sick role and the return to being her capable self within the family. While at the time of the initial interview Linda accepted her family's support in the light of her limitations, this time Linda wants a more balanced form of support. We can see some resentment towards her family, which she perceives focuses too much on her limitations rather than her abilities. The type of support she prefers acknowledges her limitations without making her feel incapable of things. She explains the importance of that here:

I just think that it's most important when people are ill that when I say to them would like to do so and so, and people say oh no no. You have to support people but don't smoulder them, you know, I think it is most important because you tend to think, you are not well and you are losing it and by people sort of not smouldering you, because they love you so much, they don't smoulder you but they don't give you a chance to have a go.

Linda's partner seems to understand her needs and also talks about trying to monitor her abilities, while facilitating her return to previous rhythms of life. It might be, however, that he is not aware of the potentially negative impact on Linda if this balance is not achieved. Regardless of the desire to regain her role in the household, Linda still appreciates the support from her husband, especially in relation to her stoma. Here she describes the situation of going out for a meal during the holidays when her stoma leaked and they had to go back a couple of miles to the hotel. While Linda is clearly very distressed by the situation, she appreciates the patience of the husband in dealing with that:

I said I just feel so degraded, why is this happening? You know, and he [partner] is so patient, and he said we will just go back to where we started, we can come here another day.

Linda's recovery also has a positive impact on her partner. While at the time of the first interview Linda talks at length about the feelings of hopelessness of her partner, here we can see how the improvement in her strength and the diminishing threat of death is mirrored by improvements in her partner:

Well he is much better because I am much better, it is when he, I think he was thinking that he was going to lose me that he lost all hope and he was just floundering.

Chris, unlike some of the participants, seems to have many opportunities to share his experience of recurrence with people and embrace the openness about his experience with his family as well as the wider community. During the initial interview, Chris describes the transition in his approach to sharing the news of recurrence. While initially he feels reluctant to talk about the diagnosis, he makes a decision to share the news of recurrence with people. Once he starts to share his experience, Chris finds that it has a positive impact on his wellbeing. We can see how he goes from keeping the diagnosis to himself to sharing it with a wider community including his friends and clients. In fact, by sharing his experience he also aims to raise awareness about the symptoms and encourage people to take up the test offered to people over 60, as this is how Chris has initially been diagnosed. He seems to be on a quest of trying to raise awareness of colorectal cancer:

I felt better in the end through talking about it so all my friends and all my clients, all my clients know what the problem is and some of them individually phone me up and my colleagues are always being asked how is Chris [refers to himself].

Similarly to the initial approach by Linda, Chris values the support from his family and talks about the caring approach of his partner, calling her “Nightingale nurse”. The support from his sons is also appreciated, which takes form of daily visits and phone calls. This in Chris’ eyes is “genuine support”, which he contrasts with “token support”. The token support is here described as not engaging with him and commenting on the external signs and interpreting them as being well:

My wife, she has been fantastic, she is like my own flying Nightingale nurse. [...] And the same with my two sons. [...] If there is anything you need, we will be there. We will take you anywhere you want to and they’re very good like that. [...]. I think you need support from the family and it has to be genuine support, and not just the token support. [...] You know when it is genuine and you

also know that when someone is just saying you are looking well, fine, bye- It's not genuine.

This willingness to share is in contrast to the loneliness of certain aspects of Chris' recurrence. While we can see the positive aspects of sharing the news of recurrence and the progress of his treatment, he also faces a number of challenges in being able to be part of the social life he used to have, mainly because of the lack of control over his bowels in the evenings. Here Chris describes a situation of spending a night in the hotel recently and the impact of bowel problems on his ability to spend time with people:

The other part of that problem is that when the motion start to happen it is not a like a normal population when you would go to the loo and that is the end of it I may go a little bit 20 times so I am backwards and forwards and backwards and forwards and it may be minutes between each time or it may be 15 minutes so I am in and out and if you were in the hotel situation you can't rush backwards and forwards to the lounge. It's embarrassing so once motion starts to happen you have to stay in the room until the next day.

During the second interview, Chris continues to talk about the positive impact of sharing his experience with people. Similarly to the initial interview, he sees it as contributing to his well-being as well as helping others by raising awareness. We can however see the shift in Chris' approach. While at the first interview, he recalls his initial hesitation in sharing the experience, here he describes himself as a "big believer in talking to people". Interestingly, he starts the sentence with we (him and his partner) but quickly changes to I, repeated three times which may suggest that this approach is not necessarily shared with the partner:

We, I, I, I am a big believer in talking so people I meet I talk about it because it helps me and it may help someone else to go and take the tests. It's very easy to sit and let the problems manifest in your own mind and we find that this made a big difference.

His partner Louise also talks about the benefits of talking to people, but this is mainly in relation to her friends. It might be that while they both find

talking about their experience beneficial, sharing serves a different purpose for each of them.

Chris also continues to welcome support from his family, which he sees as important in lessening his distress. Similarly to Linda, the issues related to his bowel seem to be shared with his partner. He sees it as a joint effort, evident when using “we”, when discussing the decisions regarding a stoma. Even taking a medication to stabilise the bowels is a joint activity in Chris’ eyes. Food preparation and diet seem to be adjusted to fit Chris’ illness and his wife plays an important role in facilitating this. This approach to sharing the responsibility of this aspect of illness is also clearly visible in Chris’ partner account:

We looked at going back to stoma again, however I have tried not to go that route. I want to stay without a stoma. This is why we are doing the diet record programme so we can see if we can improve things. We improved the medication, what we, we take a lot of emodium which helps to stabilize the bowel, and we take couple of another: what is this medication X [saying to partner]?

Regardless of his improvement in his physical strength, Chris, unlike Linda, George and Kate, seems to welcome continuous support from his family. He comments on the reduced levels support he has received from friends and contrasts it with the consistency of the support received from his children:

Yes, over the last couple of months people are not phoning me every day now. They think there is a pretty good chance that I might be a little bit longer here. [...] My boys still contact me on a daily basis literally. [...] They are grown up with their own families but nothing is too much trouble which is how it should be.

It seems that in some aspects, Chris continues to struggle with sharing his experience of recurrence with people. Sharing meals seems to be one of the aspects when Chris seems to be faced with difficulties, as people do not seem to be accommodating to the restricted diet he needs to have. We can see the distinction here between sharing emotions and talking about

cancer, which he is so willing to do, and the private side of bowel recurrence, which usually takes place at home:

And then the problem comes with the social life if you go to friends for dinner and of course they don't understand what you can eat and can't eat and you suddenly find that you have dinner in front of you that a) you couldn't eat it the quantity of it to start with and b) 50% of it you should not be touching anyway. [...] As I say most of the time, we can control that by not eating and then eating when I am going to be a home where it's very private and it's ok.

Louise also expresses her concern about this aspect of his illness and talks about the limitations of unpredictable bowel movements on her partner's life. While she acknowledges the losses to her life, she seems to be mainly preoccupied with the psychological and physical suffering of her partner.

5.4.6 Part B- Discussion of the Cross Case Superordinate Longitudinal Theme 3: “Sharing and not sharing the experience of recurrence”

The third Cross Case Longitudinal Superordinate Theme: *Sharing and not sharing the experience of recurrence* describes participants' accounts of the extent to which they shared their illness experience with loved ones, friends and wider community. Firstly, I will describe the challenges of sharing the emotional impact of diagnosis with people, especially when facing one's own mortality. Related to this, I will describe the benefits and limitations of patients accessing support from other people. I will explore the issues related to sharing the day-to-day life with people following cancer diagnosis and the impact of practical support for the patient.

Talking about the meaning of diagnosis and facing one's own mortality has been recognised as one of the key challenges for patients and their families. In the current study, patients with a poorer prognosis did not seem to discuss the news of recurrence with people, as this was avoided either by families or the participants. Families often referred to the severity of the situation indirectly or even refused any discussions about the possibility of death and encouraged a positive outlook in patients. Negotiating understanding of the diagnosis with children was also found to be very difficult. For families with younger children it was about minimising the disruption to their lives, while trying to warn them about the threat of death.

For families with adult children the diagnosis tended to become a taboo subject. In contrast, while patients with a better prognosis also experienced some challenges in talking to people about cancer, their difficulties were not as severe. Difficulties in instigating discussions about death have been described in other studies with patients with metastatic cancer, with patients taking a leading role in introducing the topic (Chunlestskul et al., 2008a). Some studies also reported that patients felt that their worries were dismissed as people were not able to face them with them (Vilhauer, 2008). In one study, ovarian cancer patients felt that when the cancer recurred they lost the positive image of a cancer survivor, which contributed to changed reactions from other people (Ekwall et al., 2007). Feeling silenced by societal norms in talking about one's mortality has also been previously reported as a barrier (Vilhauer, 2008). On the other hand, the reluctance of patients to report both physical and emotional suffering was also previously acknowledged in a study with metastatic breast cancer patients (Vilhauer, 2008) and suggests that attempts by patients to carry on as normal was to a large extent not so much a choice, but rather something that was imposed by family or people around them. A reluctance to report other difficult topics such as pain was also recognised in other studies, where patients did not share their feelings of pain with families unless necessary, and this was seen as a way of maintaining normality in the families (Coward and Wilkie, 2000). The current study further highlights the difficulties of patients to discuss their fears of the possibility of or even approaching death as well as the importance of protecting not only their loved ones, but also themselves.

Regardless of the prognosis, having access to people who are able and willing to share the burden of the emotions and concerns generated by the diagnosis is well recognised. In the current study, the sources of support varied and seem to include Clinical Nurse Specialists, online communities, family members, fellow patients and psychological services. These sources provided reassurance when family members were not willing or felt unable to talk about patients' wishes or the reality of the situation, for example prognosis. Similarly, not putting a pressure on a partner to be the sole provider of support, or worrying about the future of a partner following death, motivated seeking additional support. For one patient, sharing their experience outside the cancer community also served a purpose of trying

to educate people and normalising bowel cancer. As the majority of people willing to support patients were either fellow cancer patients or people working in cancer services, they had direct or indirect experience in dealing with challenging topics. Previous studies also highlighted that discussing death with people outside the cancer community was often difficult as it generated unwelcome reactions (Chunlestkul et al., 2008b). Women with ovarian cancer recurrence found themselves sometimes struggling to share in fact both positive and negative aspects of recurrence with people not affected by cancer (Ekwall et al., 2014). This was sometimes related to the fact that the need for support could quickly change as it seem to fluctuate depending on the news received or patients' physical well-being , thus inhibiting seeking support from people who were not familiar with the changing nature of recurrent cancer (Vilhauer, 2008). Other studies highlighted these difficulties further as it was found that having the same diagnosis meant sharing the same emotions as well as concerns and, in turn, this facilitated feelings of closeness and understanding (Vilhauer, 2008). The current study highlights the importance of shared experiences of cancer as facilitating empathy as well as understanding, but also draws the attention to the fact that while the support received from the cancer community was clearly beneficial, it could also create wider gaps between patients and their families.

The extent of discussions about cancer was also to some extent visible in the extent to which participants' day-to-day lives were shared with their families. Patients who were facing poorer prognosis did not share the preparations for death with others. Families often found it too difficult to discuss this and in light of that, patients still engaged with their own preparations for death by thinking about their funeral or even arranging it, or refused to make any changes to their previous lives. Also, not being able to contribute to daily family life because of demanding treatment regimes meant that arranging one's funeral and sorting one's affairs was considered to be a way of minimising the distress in families after one's death. In contrast, not wanting to engage in talking about death by patients also meant that they wanted their families to maintain the previous rhythms of their lives.

Patients who have undergone surgery seemed to face difficulties in sharing their experience of a possible recovery from the treatment they have

received. Receiving practical support from people was valued, especially in the period of recovery from treatment. Being provided with meals or having one's work schedules changed to provide support was appreciated. In contrast, regaining normality in the family and rejecting the sick role for patients who had slightly better prognosis and had recovered physically from the treatment was also important. Patients and consequently their families had to face an important transition from going through treatment (which usually involved losing their roles in the family) to slowly regaining their roles once they recovered. This had to be negotiated within families and was not always easy.

Previously, patients have also described the complexity of providing and accepting practical support. On one hand, some studies reported attitudes of overprotection from family and friends and feelings of expectations from others to adopt the sick role and rest all the time (Vilhauer, 2008), while receiving support from people in accepting limitations of the illness was found helpful in a study with patients with relapsed myeloma (Maher & De Vries, 2011). Studies also highlighted that not providing families with too much information or attending hospital visits on their own were examples of trying to minimise the burden (Ekwall et al., 2007, Maher & De Vries, 2011, Sarenmaln et al., 2009). Maintaining previous life was important when dealing with the diagnosis of recurrence but often it meant that cancer became an unspoken reality rather than an acknowledged part of life (Maher and De Vries, 2011, Vilhauer, 2008). While these articles seem to suggest the difficulties of balancing feeling supported and rejecting the sick role, the current study highlights how the perceived prognosis may influence the dynamics in the family.

In the current study, bowel problems also highlighted to a certain extent the loneliness of the experience, with patients preferring to manage these problems within the privacy of the home, with some involvement from partners. A lack of understanding amongst others regarding patients dietary requirements often made dining out and dining with friends problematic, and was one of the common examples of difficulties in sharing life after cancer with other people. Having to limit social outings because of unpredictable bowel movements was also common. Sharing the daily rhythms of life was also found to be difficult in other studies, as cancer treatment could dictate what was achievable during the day which families

and friends found sometimes difficult to accept (Ekwall et al., 2014). Equally, studies looking at the experiences of patients with bowel cancer at the time of initial diagnosis also highlighted the difficulties of managing social outings as a result of bowel surgery (Sahay, et al., 2000, Dune et al., 2006). The current study highlights that these issues are also important at the time of recurrence and may have in fact a greater impact in the context of uncertain prognosis.

Chapter 6: Partners' experience of colorectal cancer recurrence

6.1 Overview of the chapter

In Chapter 6, I present the analysis of the longitudinal qualitative study on partners' experiences of recurrence. I first present participants who contributed to the study. I then present Three Cross Case Longitudinal Superordinate Themes which describe partners' experiences.

6.2 Participants: partners

The final sample included 5 partners (3 females and 2 males). All partners were partners of patients included in the patients' study. The partner of one patient declined to take part. The summary of the partners which were interviewed at both time points is presented in Table 6.2.

Table 6.2 Summary of participants (partners)

Pseudonym	Sex	Age	Recruitment method	Occupation
Michael	Male	71	Social Media	Retired
Victoria	Female	42	Social Media	Business Manager
Alan	Male	62	Social Media	Self-employed
Anthony	Male	74	NHS (postal)	Retired from paid work
Louise	Female	59	NHS (postal)	Shop Assistant

6.3 Pen portraits of the partners

Michael had retired from paid work. His family lived a long distance away and as a result he had limited access to support. He experienced severe financial difficulties following his wife's diagnosis of cancer. He had experienced cancer (prostate) himself two years before his wife's initial diagnosis.

Victoria-partner to James

Victoria was working full-time when her partner was initially diagnosed with cancer. Her partner experienced a second recurrence by the time of the

first interview. After the first recurrence, she felt unable to continue both working full-time and providing care to her partner. Consequently, she took long-term paid leave from work. By the time of the second interview, she still felt unable to return to work and had to start an official termination of contract procedure. She had two young children. She had received some counselling to be able to cope with her partner's diagnosis.

Alan-partner to Johanna

Alan continued to work with his business throughout the initial and recurrence stage of his partner's cancer. Following the initial diagnosis, he asked his partner's sister to come and help him run the household and care for his partner while she was undergoing chemotherapy. He also asked for her help following the news of recurrence, but he found that he was able to cope better and his partner's sister returned home. He had two adult sons, one living with him and his partner.

Anthony-partner to Linda

Anthony had retired from paid work. His two adult children who lived away from home and he took responsibility for caring for his partner following the recurrence. Before the diagnosis, he used to volunteer for a national charity but was unable to do so while his wife was undergoing treatment for recurrence. He slowly returned to this work with the support of his family.

Louise-partner to Chris

Louise was employed while her partner was undergoing treatment for both the initial and recurrence stage of cancer. She took annual leave to be able to be with her partner. Her adult children lived away from home but would call her on a daily basis.

6.4 Findings

In this section I present three Cross Case Superordinate Longitudinal Themes: Theme 1: "*Trying to make sense of patient's unpredictable illness*", Theme 2: "*Trying to share the burden of caring*" and Theme 3: "*Dealing with loss of their previous life and their partner as they knew them*" (Figure 6.4). This Chapter is divided into three sections with each section presenting one Cross Case Longitudinal Superordinate Theme (Part A), followed by a discussion in relation to the current literature (Part B).

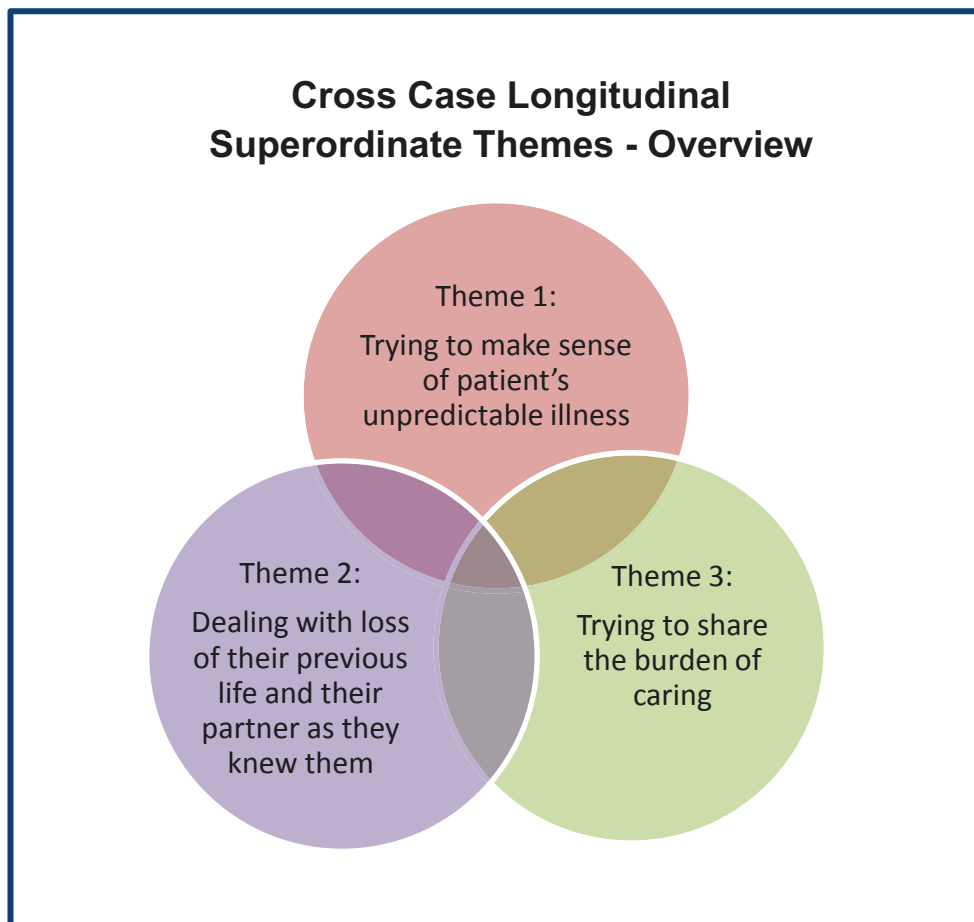


Figure 6.4 Cross Case Longitudinal Superordinate Themes – Overview

6.4.1 Part A-Cross Case Longitudinal Superordinate Theme 1: “*Trying to make sense of patient’s unpredictable illness*”

The Cross Case Longitudinal Superordinate Theme 1: “*Trying to make sense of patient’s unpredictable illness*” describes the partners’ experience of the patients’ changing prognosis and treatment options and their attempts to adjust to these changes. It also highlights their evolving understanding of cancer as an illness.

The diagnosis of recurrence is a distressing event, generating a number of emotions. Partners try to make sense of the severity of the situation. The initial diagnosis seems to be an important reference point for participants for the way in which the diagnosis of recurrence is understood by them. While some factors, such as an unfamiliar treatment mode and lack of hope, can magnify their distress, perceiving the risk of recurrence as high

can lessen the shock of a diagnosis. The process of trying to understand the patient's illness continues following completion of treatment for the recurrence, with some partners being able to regain hope for the future, while others continue to struggle. Hope seems to be fuelled by positive scan results as well as seeing the patient regain physical strength or return to their previous activities.

As previously described in the Methodology chapter, Table 6.4.1 sets out the Cross Case Longitudinal Superordinate Theme 1 and then, for each partner, their individual within case Longitudinal Superordinate Theme, together with their individual Superordinate Theme at Time 1 and at Time 2, and Subordinate themes identified.

Table 6.4.1 Cross Case Longitudinal Theme 1: Trying to make sense of patient's unpredictable illness

Cross Case Longitudinal Superordinate Theme 1: Trying to make sense of patient's unpredictable illness		
<p>Louise: Looking into the future after the uncertainty of the news</p> <p>Time 1: Adjusting to the meaning of diagnosis</p> <p>At the time of the first interview, Louise describes her initial distress following the news of her partner's recurrence. With time, she seems to be reassured by her partner being offered surgery. This seems to continue after the first clear scan, when she balances the uncertainty of the future with at least temporarily good news.</p> <ul style="list-style-type: none"> ✓ <i>Balancing distress with treatment options</i> ✓ <i>Seeing the initial diagnosis as most challenging</i> ✓ <i>Trying to balance worries about the future with positive news</i> ✓ <i>Focusing on the present to maintain fragile well-being</i> 	<p>Anthony: Celebrating hope after refusal to give up</p> <p>Time 1: Seeking chances of survival within the threat of death</p> <p>At the time of the first interview, Anthony describes his despair following his partner's news of recurrence. This is magnified by interactions with clinician whom he perceives as giving up on his partner. As a result, he tries to reject the diagnosis by seeking a second opinion.</p> <ul style="list-style-type: none"> ✓ <i>Feeling cheated by partner having cancer</i> ✓ <i>Rejecting the hopelessness of the situation and prognosis</i> ✓ <i>Seeing broken promises as giving up on his partner</i> 	<p>Alan: Holding on to the feeling of lessening emergency</p> <p>Time 1: Celebrating the diminishing threat of immediate death following devastating news</p> <p>At the time of the first interview, Alan describes his shock and distress after hearing the news of his partner's recurrence. This is magnified by his wife not being able to have surgery. With time, he tries to hold on to any positive news, and celebrates the results of the first scan.</p> <ul style="list-style-type: none"> ✓ <i>Perceiving his wife as cured magnifying the impact of recurrence</i> ✓ <i>Being overwhelmed with the severity of the situation in contrast to the initial diagnosis</i> ✓ <i>Celebrating the "best possible news" against an uncertain future</i>

Table 6.4.1 Continued Cross Case Longitudinal Theme 1: Trying to make sense of patient's unpredictable illness

Cross Case Longitudinal Superordinate Theme 1: Trying to make sense of patient's unpredictable illness		
<p>Time 2: Celebrating “beating cancer”</p> <p>By the time of the second interview, Louise’s partner has had two clear scans and she tries to balance this positive news with the uncertainty of the future. However, new symptoms cause huge anxiety as they may mean not only another recurrence but also a loss of hope.</p> <ul style="list-style-type: none"> ✓ <i>Negotiating the uncertainty of the future with her partner</i> ✓ <i>Escalating concerns about meaning of symptoms</i> 	<p>Time 2: Celebrating a chance of the future</p> <p>At the time of the second interview, Anthony reflects on the change in his partner’s situation since the first interview. He focuses on a successful operation and recent clear scan, which enables him to feel more optimistic about the immediate future.</p> <ul style="list-style-type: none"> ✓ <i>Carefully planning and celebrating the possibility of the future</i> ✓ <i>Celebrating an “intermediate future” in light of clear scans</i> 	<p>Time 2: Holding on to diminishing threats of death</p> <p>Over the course of time since the first interview, Alan’s partner has had two scans showing that the tumour is receding. He seems to hold on to this news in the context of the fragility of his partner’s situation. He minimises his worries about the next scan and tries to take reassurance from the previously encouraging results.</p> <ul style="list-style-type: none"> ✓ <i>Celebrating news of his partner cancer continuing to recede</i> ✓ <i>Holding to the certainty of the current scan until the next one</i>

Table 6.4.1 Continued Cross Case Longitudinal Theme 1: Trying to make sense of patient's unpredictable illness

Cross Case Longitudinal Superordinate Theme 1: Trying to make sense of patient's unpredictable illness	
<p>Victoria: Giving up hope for cure while facing her partner's suffering</p> <p>Time 1: Struggling with unpredictable disease while slowly giving up hope for cure</p> <p>At the time of the first interview, Victoria describes her despair and shock after hearing the news of recurrence, which is mainly related to the uncertainty of her partner's situation. The unpredictability of the situation seems to continue after her partner starts chemotherapy treatment. While she hopes that her partner can have further surgery, she also realises the physical limitations of her partner and worries about the severe effects of the treatment.</p> <ul style="list-style-type: none"> ✓ <i>Being shocked by the return of cancer in light of initial prognosis</i> ✓ <i>Facing unpredictability of the illness while slowly giving up hope for cure</i> ✓ <i>Struggling to make sense of an unpredictable disease alongside health care professionals</i> 	<p>Michael: Waiting for another recurrence</p> <p>Time 1: Adjusting to diagnosis while fearing the future</p> <p>At the time of the first interview, Michael describes the news of recurrence as being less shocking than the initial diagnosis. This seems to be related to being warned about the high risk of the cancer returning and his partner experiencing quicker recovery. Following the surgery, he worries about further recurrence, despite clear scans. He tries to reassure himself by focusing on treatment options his partner might be offered if the cancer did return.</p> <ul style="list-style-type: none"> ✓ <i>Experiencing the initial diagnosis framing understanding of the recurrence</i> ✓ <i>Balancing worries about the possibility of further recurrence with treatments available</i>

Table 6.4.1 Continued Cross Case Longitudinal Theme 1: Trying to make sense of patient's unpredictable illness

Cross Case Longitudinal Superordinate Theme 1: Trying to make sense of patient's unpredictable illness	
<p>Time 2: Balancing desire to prolong her partner's life against the relentlessness of cancer</p> <p>While at the time of the first interview Victoria still hoped that her partner could have further surgery, by the time of the second interview she seems to focus mainly on the burden of treatment on her partner. The unpredictability of side effects means that she is unable to sometimes enjoy moments of her partner's intermittent periods of recovery. Test results provide the only reason to continue with treatment.</p> <ul style="list-style-type: none"> ✓ <i>Balancing the impact of treatment on quality of life against unwillingness to cease the treatment</i> ✓ <i>Facing intermittent and unpredictable periods of recovery to enjoy with partner</i> 	<p>Time 2: Balancing between hope and acceptance of future disease progression</p> <p>By the time of the second interview, Michael is preoccupied with worries of another cancer recurrence. As his partner suffers from ongoing symptoms, he does not seem to be reassured by clear scans. He also seems to be influenced by the negative image of cancer in his family. However, his partner's active attitude towards cancer seems to challenge this approach.</p> <ul style="list-style-type: none"> ✓ <i>Living by waiting for recurrence while hoping for a clear scan</i> ✓ <i>Balancing between positive and negative images of cancer</i>

Partners vary in the extent to which they are able to make sense of the diagnosis of recurrence. Both Louise and Anthony are devastated following the news of recurrence, as they are overwhelmed with the perceived severity of the situation. With time, they are able to look into the future and be reassured, firstly by the patient being offered surgery and then by clear scans and the patient regaining their physical strength. In contrast, Alan struggles with trying to make sense of the situation, mainly related to the poor prognosis and the treatment offered being only chemotherapy, but with time is also reassured by the effectiveness of the treatment. Victoria's experience resembles the initial experience of other partners, but also highlights further challenges. Finally, Michael's experience differs as he does not seem to regain hope for the future but is focused on the risk of another recurrence.

The news of recurrence is hugely distressing for Louise and her reaction is embodied by actually fainting following the news, possibly because of the perceived meaning attached the diagnosis at this point. Although informed by the nurse about surgery being a possibility, it does not seem to lessen the impact of the news at this stage. Only after the option of surgery is confirmed and explained by the clinician does the operation seem to provide some balance to the news:

X's [patient] Colorectal Nurse, and she said that unfortunately a spore had got loose and it had gone into his liver. So we knew about that and we both sat here crying, you know, because we thought, oh god, you know. But she said, I really believe that it's in a place where it can be operated on. And then we went to see Mr X, the oncologist. [...] And I mean that was, that was really, really distressing. When we were told that it had gone into the liver, I think I did my fainting bit, because I do that now and again if it's really bad news, you know [...]. He [oncologist] said that it's not nice to know that it's gone into the liver but we can operate and that is good news. If it had been up near a major artery, they wouldn't have been able to operate.

We can see how Louise's thinking about the operation seems to have evolved. With time, the chance of an operation is appreciated more by her as it is contrasted with the option of only having the tumour "shrunk down":

He was lucky that he could have the operation to remove the tumour. Lots of people aren't that lucky, they just have the tumour shrunk down with radiotherapy or something, you know. Yes, so that's what I meant, that he was lucky that it was operable.

It seems that once the treatment is over, the meaning of recurrence changes to Louise. The acknowledgement of the potential stress associated with the operation is superseded by the quick recovery from the operation, which in turn seems to significantly minimise the impact. The dramatic contrast between recovery periods following recurrence and initial diagnosis seems to contribute to a perception that in fact recurrence may have been less serious than initial diagnosis:

Well I haven't really found it challenging at all because he had the liver operation done, I mean, obviously, it's another operation and it's a very anxious time, but he had the liver operation done on a Wednesday, and he was home on the Saturday, and he recovered really, really well.

While Louise seems to focus on the quick recovery when comparing the initial diagnosis and recurrence, Chris, her partner, seems to focus on the longer waiting period leading to operation. Here, we can also see how different meanings seem to be attributed to initial diagnosis and recurrence. The initial diagnosis is perceived as unfair. In contrast, the familiarity of the pattern of action, namely surgery following the news, seems to lessen the distressing impact of recurrence. Although the news of recurrence is difficult to take, the news is still considered as "not as bad". It seems that some effective coping strategies, which have been developed at the initial stage, are useful at this time as well:

Well the initial diagnosis was shocking, devastating, because cancer, you know, what have I done to deserve this, sort of thing. [...] But it wasn't as bad with the liver tumour. Well because he'd already had cancer hadn't he, and we'd got over that. [...] But I suppose we, we were told it was operable and we'd already had a massive shock with the initial bowel cancer, so one more thing thrown at us sort of thing, we were able to cope better I think, yes.

Following the operation, the focus for Louise is on monitoring her partner's progress. She seems to balance the lack of guarantees regarding future disease progression with a celebration of the first clear scan:

But he [surgeon] said, I can't sit here and say that this cancer won't come back again in years to come. He said, I don't want to give you any false hope. [...] So we'll see what Mr X [surgeon] says when we go for that appointment, and hopefully that will be good news as well.

While Louise seems to maintain that she is "coping well" and "doing well" throughout the interview, we can see intermittent moments of distress, which seem to be brought on by previous experiences of cancer in her family and unwanted memories of the possible meaning of the diagnosis as a life-threatening illness:

Yes, I do get down sometimes but I'm not in floods of tears all the time or anything like that. And I tend not to think of the future, I don't want to think of the future and will it come back or anything like that, because cancer is horrible, I lost my dad with cancer, and my mum. It's horrible isn't it, it's horrible.

By the time of the second interview, Louise's partner has had two clear scans and has also returned to work. This seems to provide some reassurance and she perceives her partner's return to work as evidence of "beating cancer":

He's had two clear scans. They're keeping an eye on him sort of every four months. It was only a couple of weeks ago and he had another clear scan, so that's two, which is absolutely brilliant. Hopefully, he's beaten cancer, hopefully, but you don't know do you, not really, you know. [...] And you look at him and you wouldn't even think, he doesn't even look ill does he, you know.

Chris also expresses his hope for the future as a result of clear scans. However, regaining physical strength and returning to work do not form part of his argument about the recovery. It might be that they hold more meaning for Louise, as she has been actively involved in looking after him.

Belief coupled with hope for a future without cancer, can be challenged by symptoms. Here, she describes how recent pain experienced by her partner is initially understood by both Louise and her partner as potential disease progression. She also needs to endure uncertainty in light of her partner's reluctance to seek immediate help. She seems to engage in ongoing monitoring of her partner's symptoms which, if unexpected, seem to trigger her concern:

Now he knows what it is, because he thought, when he was in so much pain, he just thought he might have had another tumour arrive or something, you know. [...] Yes, very scared, very scared. And he put up with it for quite a long time and I said: you should really go to see the doctor. And he said, well we're seeing X [clinician] in about a week's time or something. So that's what happened and he prescribed this cream. But if anything happens, if he feels unwell during the day or something like that, I get worried obviously, you know.

Similarly to Louise, Anthony at the time of the first interview struggles to come to terms with his partner's diagnosis and a very poor prognosis. However, he also describes the difficulties he experienced when his partner was initially diagnosed. The short period between the end of treatment for the primary tumour and the diagnosis of recurrence might mean that these two events are closely connected for him. As with Louise, the initial diagnosis is understood as a sudden and unexpected disruption to the planned future, which is seen as unfair. Recurrence seems to be a continuity of suffering and uncertainty. The expected recovery is challenged as his partner's life is threatened again and in fact he is faced with the possibility of death:

Both X [patient] and I feel that we've gone through life, we've ticked all the boxes. [...] Get to retirement, both get to retirement, and take some enjoyment out of what we've endeavoured to achieve, and the carpet is taken away from under our feet. You go through the operation, go through the recovery and the chemotherapy, anticipate going back to see the surgeon, say well, we're on the right road, we're getting there. No, completely opposite to what

you're anticipating, sorry mate, your wife's life is over, there's nothing I can do, go home and pass, let her pass away.

The shock of recurrence seems to be magnified by a lack of warning from health care professionals, as well as seeing chemotherapy and its side effects as evidence for the treatment being effective:

There'd been no suggestion that things weren't going well at all, had a chemo every month, all the side effects of the chemotherapy.

It seems that both the context of the news and the news itself have an impact on Anthony's approach to the situation he is facing. While Louise was able to be reassured by the clinician giving the news, Anthony is presented by the clinician with his partner's very poor prognosis, which he rejects. The perceived inappropriate speed of diagnosis seems to contribute to his approach of rejecting the prognosis given to his partner by the clinician:

They found this mass in her tummy, and his diagnosis from a two month old scan and a sort of 60 second prodding of x [patient] abdomen: I can't do anything for you. From that, they are clinically saying she was beyond any further help, which I didn't like the answer, didn't like the guy and didn't like his attitude to his diagnosis, and explained to him that I would be taking a second opinion, which we did.

The distress and suffering caused by the diagnosis seems to be magnified for Anthony by the clinician's behaviour. The holiday planned immediately following the diagnosis, thought to be the "last holiday", was arranged around an expected phone call from the clinician to confirm the plan of action for his partner. This phone call, which they do not receive, was agreed at the appointment at which Anthony and his partner learnt about the diagnosis of recurrence. We can see the impact of the broken promises from the clinician on Anthony here. The lack of contact and consequently no acknowledgement of broken promises is perceived as giving up on his partner and "declaring [his] partner dead":

Well we curtailed what was, we thought was going to be our last holiday together, midwinter down the X [city's name] where my

brother lives, and we kind of purposefully came back just to get this phone call. We waited and waited, day after day, it never transpired that he picked the phone up. X [patient] phoned up his secretary who said well, no idea what you are you talking about, there's nothing on the records that he was going even to talk to you. For my vision of what he was transpired, he had already declared [patient] dead and buried.

Anthony's partner, Linda, also describes her loss of hope when faced with the offer of chemotherapy as well as her disappointment with the way her prognosis was communicated to her. However, the distress caused by the situation seems to be more difficult to cope with for Anthony. It might be that Anthony's inability to help his partner magnifies his suffering.

As a result of this experience, Anthony decides to get a second opinion, following which his partner is given a chance of being operated on. Although provided with some hope, he has to face the uncertainty related to the treatment until the operation is in progress. The surgery provides some solution to this and by the time of the second interview, similarly to Louise, Anthony's partner has regained her physical strength following surgery, has had a clear scan, and is also informed that she does not need further chemotherapy. The diminishing threat of death seems to be the focus for him, which he celebrates in the context of the uncertainty of the future. The journey has involved a number of stages involving seeking a second opinion, being given hope, a long operation and finally his partner's slow physical recovery and clear scan. The future, taken away by the diagnosis, is not perceived as yet belonging to Anthony. However, planning for the future is now possible and celebrated by Anthony:

It's been the lowest part of my life, and it's been the happiest part of my life. Having had diagnosis last year, and telling us [...] that X [patient] had no future, and felt like the world was coming to an end, which it would have been. [...] and slowly but surely X [patient] turned the corner, and we're today, we're still hesitant to say we've got a future, but we're planning for the future.

We can see the complexity of the uncertainty for Anthony here and what the improved prognosis means to him. The clear scan and no need for further chemotherapy provide some reassurance and faith for the future

free of cancer. Although there seems to be an acknowledgement of possible future problems, the interpretation and meaning Anthony seems to attach to that seems to be a positive one. Like Louise, he seems to balance the celebration of the present with a threat of future problems. The positive interpretation is a complex one as the future seems to be seen into blocks of time: immediate and intermediate ones. The certainty of life without further recurrences seems to relate to the immediate future, which in turn allows having plans for the “intermediate one”:

They had done the tests, and there were no cancer cells in her blood, whatsoever and there was no need for chemotherapy, so we had all the faith that we could have, and there aren't any, possibly no nasty hiccups in the future, but you can never say never, never be any more problems, but I think we took it as, that there weren't any unforeseen hiccups in the immediate future or in the medium future, so therefore we could start talking about intermediate future.

Similarly to Anthony, Alan's experience of the diagnosis of recurrence is shaped by his understanding of the meaning of the initial diagnosis. His partner having clear scans following the end of the initial treatment along with information from health care professionals seemed to be reassuring, even in the context of ongoing symptoms. However, as time progresses, the existence of symptoms becomes the focus and triggers the request for another scan, which reveals that in fact cancer has returned:

So she went back for these, I think it was six month tests, which continued to indicate that it was all clear. This must have gone on for two years, so we were all feeling relieved and fairly happy about the situation. She was still having problems. Initially they'd said, well having had something like twelve inches of bowel removed, you were going to get some difficulties with that, as the body adjusted to this surgery, so we were not too overly concerned, although she was in some discomfort, but when it continued [...] and she asked for another scan again, and that's when it was diagnosed that the cancer had returned.

Here, we can see how the understanding of “being cured” is negotiated by Alan. Although he had been provided with information about the possibility

of cancer returning, this does not seem to lessen the shock of recurrence for Alan. The perception of being cured “on the face of it” seems to guide his thinking here:

They'd given a cure, they'd put the rider on it that, you know, it could return, because they, to be honest, nobody knew why it came in the first place. So if the condition's existed for, that it had existed, that it came in, in the first place, presumably they still existed, but what they were no one could say. But on the face of it, it was cured.

Here, we can see the how the treatment his partner received seems to be understood by Alan. Treatment following initial diagnosis of one tumour is viewed as “very successful”, and in fact, it makes Alan question the point of adjuvant chemotherapy. Recurrence, in striking contrast to the initial diagnosis means not only multiple metastasis, but also multi-layered uncertainty regarding prognosis and the effectiveness of treatment. The familiarity of surgery as the way of dealing with cancer is taken away at the diagnosis of recurrence and contributes to the feeling of despair:

Everything couldn't have gone better, the surgery was very successful and there was absolutely minor additions to the cancer discovered there, seemed very little. In fact, it seemed so little we wondered, do we really have to go through seven months of chemotherapy to do, what seemed to be, minimal risk. But yes, you know, belt and braces sort of approach, they did it. And at the end of it, all went to plan, you know, it was fine, declared all clear and that was it, very matter of fact. The pre-contrast on the second one, we were suddenly, it had not only returned, it had spread. No surgery this time, no prognosis could be given.

Following this uncertain period, Alan's partner had a scan, which shows a reduction in the tumour. In the context of uncertainty regarding the potential effectiveness of the treatment initially discussed, the news of tumour reduction is clearly celebrated by Alan. Similarly to the initial diagnosis, he seems to hold on to a more positive interpretation of the news and focuses on news of the treatment working and the improved odds:

I mean there are grounds, I mean we were cautioned on the one hand that it's not necessary, but clearly the first three months of

chemotherapy was effective. So you feel, you must be doing something right, although you can't take it absolutely for granted. So we're not taking it for granted but, as I say, it's a more optimistic outlook now than it was. As I say, when we went two or three weeks ago, they could have said anything. [...] We couldn't have had more positive news, which we still hope it's not over optimistic.

The "best possible news" seems to contribute to hopes that the treatment will continue to work. The lack of guarantees from the clinical team, although acknowledged by Alan, does not seem to be the focus for him. The positive results following initial treatment fuel the hope for treatment to continue to work, which in turn reduces the uncertainty:

And yes, we would go into the next scan in a lot more positive outlook than we did the last one, where it was a complete unknown, if you like.

Johanna, Alan's partner, also describes his positive interpretation of the situation; however, it is only her who raises the discrepancy in their approach. It might be that his inability to discuss this discrepancy reflects his wider difficulties in talking about the situation, also described elsewhere.

By the time of the second interview, Alan's partner has had another scan suggesting that the tumour has reduced. The positive impact of the first scan is magnified here by the results from the second scan. It seems that Alan might have hoped for cancer "disappearing" but he is willing to accept the tumour reduction:

Although that was very positive, she had been warned that, not necessarily to expect a further positive scan, it would not necessarily follow. Anyway, about June time she had the second scan, and again that was a very positive one, which lifted her morale and everybody's morale having had two, then given a three month break. As we understood it, the cancer had not disappeared but it was receding on both the occasions.

However, the celebration of apparently stable disease is understood in the context of upcoming tests. On the surface, it seems that the current good news is the focus here and until the next scan, this is not able to be

challenged. Again, the previous two scans provide reassurance and frame Alan's thinking about the situation. However, as he continues, we can see that while he is hoping for continuously effective treatment, there are still a number of possible outcomes of the next scan. In fact, the need for chemotherapy is "probable" and we can see how Alan's reframes the unwelcome need for chemotherapy in the context of the treatment providing a solution:

No, there's no feeling of uncertainty. As I say, the next appointment is in October, which we'll all be a bit anxious about. But having had, since the problem arose last December, two critical dates and it's all gone, it's all been very positive. I mean the next scan, that will be a bit anxious, as I say, this is the first scan we'll see how the thing is going without chemotherapy. Whether the receding cancer, which is what we understand from what, the cancer cells have been receding, whether they continue to recede without the benefit, that, it will be anxious. And, obviously, we'd like to see that it's continued to recede, on the other hand, the probability is that, you know, you'd expect to see further chemotherapy might be required. At least the chemotherapy seems to be addressing the problem.

Similarly to the first interview, Alan seems to be more positive about the situation than his partner, Johanna, who although also tries to hope for the treatment continuing to work, seems to also acknowledge the severity of her situation.

As was the case with Alan, the emotional impact of the diagnosis of recurrence seems to be shaped for Victoria by her perception of the low risk of recurrence following the treatment at initial diagnosis evidenced by successful treatment, her partner's recovery and subsequently his return to work. Here she recalls the experience of first recurrence as unexpected and as a complete shock. The shocking nature of the diagnosis is also highlighted by her partner, James:

They said that it's moved into liver. We were really really shocked by that diagnosis, because we were under the impression that everything had gone really well, and you know, he was doing OK, and he had gone back to work.

The distressing impact of the news is magnified by being offered only chemotherapy as a treatment. The familiar pattern of dealing with cancer by surgery is denied here and generates a reaction of “being freaked out”:

We saw the oncologist, who gave us the news, and they basically said oh, you know, there isn't an operation, which we were even more freaked out about.

The uncertainty of the situation seems to continue for Victoria when surgery for the second recurrence is no longer an option. We can see the relentlessness of the treatment here and not being able to find an option which would bring less suffering or less uncertainty. While current the chemotherapy treatment in principle lessens the uncertainty at the time, it has a significant impact on both Victoria's and her partner's life, which is difficult to deal with. Ceasing chemotherapy not only means the end of one of the effective treatments but also uncertainty regarding side effects associated with a new treatment:

I don't know, it concerns me that the only sort of option is now well we just keep on giving you chemo, again and again and again and again, and you know. Once it stops working and moving on to other drugs, that's another whole emotional roller-coaster of side effects and anxiety again.

Victoria also seems to struggle to make sense of the illness as the relentlessness of the treatment does not seem to make the difference they expected, which in turn is difficult to accept. She seems to lack support from health care professionals in making sense of the situation. Here, the typical pattern of recurrence presented to Victoria is challenged when her partner was diagnosed with bone metastases at the time of the second recurrence. This, in turn, seems to have an impact on her trust in clinicians, who cannot provide clear answers regarding the expected outcomes and the nature of the tumour:

I think he's baffled some of the doctors and things that we've seen, because we were always told in the beginning that bowel tumours wouldn't go in to the bones, but you know, here we are.

By the time of the second interview, the major focus for Victoria seems to be the impact of treatment on her partner. The recent change to a different chemotherapy regime has resulted in increased side effects and as a result seems to have triggered thinking about the impact of the treatment on her partner's quality of life. However, worries related to this are quickly challenged by the uncertainty regarding the future effectiveness of the treatment which seems to lead to more acceptance of the situation. At the same time, she also hopes for a change of treatment, which may bring fewer side effects:

Can't we find another one with not as many side effects? So yeah, but you know, on the other side, you've got to just kind of go with these things while they still work and, you know, hopefully some of the other ones that he's got left to try won't be as bad, and won't be, have side effects that he's had, because he's suffering a bit with some of them at the moment.

In fact, "stable scans" seem to be the only motivation to continue with the treatment. We can see how the previously established routine of "one bad week and one good week" has been challenged again, and again needs adjusting to. The loss of the good week is difficult to deal with:

He has been feeling a lot more tired, a lot more sick, really noticeably not able to do very much. But his scan has shown that everything's stable and there's no changes, so it's obviously doing what it should be doing, but it is quite hard going in terms of his like wellbeing. He's just in bed quite a lot of the time and he's just really exhausted most days, so yeah, that's been quite difficult.

The uncertainty seems not only to relate to future treatment options but also seems to affect day-to-day living. The fluctuating nature of the illness, characterised by unpredictable decline, prevents Victoria and her partner from planning. Even the security of a brief period of physical recovery before the next chemotherapy is challenged by intermittent periods of decline, which may prevent them from doing carefully planned activities. We can see the impact of the loss of opportunity as they have to wait another two weeks:

He might arrange to do something, you know, a couple of days before he goes in for his chemo, but even then sometimes you know on the morning he won't feel well, or he'll have one of his headaches or whatever, and that will, if you've planned to go and do something together when the kids are at school, we'd have to sort of cancel it and then it's another sort of two weeks before he's feeling vaguely OK again.

While the initial diagnosis of colorectal cancer seems to be an important reference point for Anthony, Alan and Victoria, it also is significant for Michael, but in a different way. He seems to have gained an in-depth understanding of colorectal cancer following the initial diagnosis from both experts as well as from his own reading. While he acknowledges his distress when hearing the news, his knowledge about the possibility of cancer coming back seems to lessen the impact of news on him as he finds it less shocking than the initial diagnosis:

I did a lot of reading, did a lot on the Internet. We've got a friend who is a very highly qualified nurse, and did, had quite a lot of conversations with her, and she said that there was a, this, I was told that there was this possibility that it could either go to the liver, brain, bone, lung, and it never really came as a surprise. But, yeah, it was, it was an upsetting time, but it wasn't a total surprise or shock that it had spread to the liver.

Similarly to Louise, the emotional impact of recurrence seems to be also mediated by the severity of his partner's physical suffering. While Michael's partner experienced major complications and side effects following treatment for the initial diagnosis, a quicker recovery following recurrence seems to lessen the distressing impact of the diagnosis and is surprisingly "easier" for Michael. In fact, he seems to compare the experience to having a baby, which seems to suggest that he tries to normalise the experience of recurrence:

Yeah, I think that it was easier, if that's the right word, the second time, I suppose it's a bit like having, having a baby I suppose, the first one you have is difficult, second one is a bit easier. The only way you can describe it, it was easier the second time. Alright, we knew that it was major surgery, what they'd done, but I was, I wasn't

the same emotionally the second time as what I was the first time, she was poorly, but she wasn't as poorly as she was the first time.

However, as time progresses, we can see the multiple layers of uncertainty Michael has to deal with and how he tries to prepare himself for different scenarios. Whilst an awareness of the possibility that the cancer could return after initial treatment seems to lessen the shock, the news of recurrence is nevertheless contrasted against the assurance that clinicians “got everything” at the time of initial diagnosis. Clear scans seem to provide some comfort, at least temporarily, but Michael also seems to prepare himself for the possibility of cancer progression by balancing the possibility of another recurrence with treatment available to deal with this. Here, just like Louise, his previous experiences of cancer in the family seem to influence his thinking as well but he tries to draw reassurance from the progress in medicine and the changing image of cancer. This belief seems to be strengthened by information from the Clinical Nurse Specialist:

All the tests are clear, everything's clear, I just, I just hope that it doesn't, but at the same time we know that it's not like in the days when my dad died in 1968, they gave him three months to live and he died in three months, because today they would have operated [...], but they didn't do it then. So we know that if something does happen, that at least, X [CNS] told her, you know, alright, if it pops up in your lungs we'll sort it, you know, we've been told that, and I think it's, at least we know if something does happen at least there's people there that can help.

Regardless of the clear scans, the symptoms experienced by his wife seem to trigger anxiety about another cancer recurrence. The dramatic weight loss of his wife, highlighted by listing the numerous changes to her body, is clearly a worry for Michael. In fact, we can see the severity of Michael's concerns when numerous sources of evidence cannot provide the reassurance he needs. The visible evidence, which weight loss here represents, seems to trigger anxiety regardless of less visible sources of evidence:

She can't wear her engagement ring, they just, she puts her hand like that and they slide off. That is a concern, why, because they don't know why she's losing weight, when everything, all the tests

they do say there's nothing wrong, there's nothing, you know, the blood tests, the CT scans, MRIs, they're saying there's nothing wrong, there's got to be something, but it is, that is a concern, it's a big concern for me.

The focus on symptoms is also visible in Kate's account, when multiple tests cannot provide reassurance in the context of more visible changes such as weight loss.

By the time of the second interview, the fears of another recurrence seem to be at the forefront of Michael's thinking. While he still has hope that the scan is going to be clear, "waiting for recurrence" appears more likely to Michael. The knowledge of where cancer could spread, described at the first interview, seems to still affect this thinking about possible disease progression:

It's almost if you're waiting for, she had a CT last week and we go and see the oncologist on Thursday, it's almost as if you're waiting to be told that it's appeared somewhere else, you know. You hope it doesn't, but we've been told there's every likelihood that it will.

While Kate also expresses her anxiety about the future, she also tries to gain some reassurance from the scans. It seems that while Kate wants to balance uncertainty with positive results from scans, Michael is more suspicious of the situation and sees another recurrence as almost inevitable. Similarly to the initial interview, the existence of ongoing symptoms is a worry for Michael. The threatening meaning of symptoms is visible here in the context of numerous negative experiences of cancer in his family. His partner's active approach to cancer, for example by doing exercise, is in striking contrast to his family member's approach and seems to represent a new way of thinking about cancer, namely as "just another illness". Rejecting the notion of being controlled by cancer by taking exercise is viewed positively by Michael and seems to be fuelled by his partner's approach:

I don't know, but from what X [patient] been through the last couple of years, it's changed my outlook if you like, the way I feel about cancer, you know, you don't be frightened of it, you get up and you do something, and it does, it's proved that it's helped her, and it's

helped other people that we know, by actually getting up and that you don't let it beat you, it's just another illness.

6.4.2 Part B- Discussion of the Cross Case Superordinate Longitudinal Theme 1: “*Making sense of patient's unpredictable illness*”

The first Cross Case Longitudinal Superordinate Theme: “*Trying to make sense of the patient's unpredictable illness*” describes the struggles partners face in adjusting to a changing prognosis, available treatment options, as well as their understanding of the illness. The nature of these challenges seems to vary according to the phase of the recurrence stage, from diagnosis through treatment and further monitoring. Firstly, I will describe the impact of the diagnosis with a focus on how previous experiences and understanding could have a potential impact on how partners perceive the news of recurrence. Secondly, I will discuss the relationships between uncertainty and the treatment offered with a focus on the treatment effectiveness and treatment burden. Finally, I will discuss issues related to aims of the ongoing scans.

In the current study, partners described a number of emotions on hearing the news including shock, despair and disbelief. The emotional impact of receiving news about a patient's recurrence on partners has also been shown in previous qualitative studies exploring the experiences of recurrence in non-colorectal cancer groups, which highlighted a range of responses following patients' diagnosis of recurrence, including anger, frustration, shock and disbelief (Chekryn, 1984, Vivar et al., 2010). A number of quantitative studies have also indicated that partners experience a high level of distress when cancer is advancing (Northouse et al., 2002). Similarly to studies exploring the experience of patients with cancer recurrence, research so far has not explored how the emotional impact of the news of recurrence may be dependent on previous experience.

In fact, the emotional impact of the diagnosis of recurrence on partners in the present study seemed to be dependent on a number of factors, which could either magnify or lessen the distress following the news. These factors were related to understanding and perceptions of the initial treatment, time since the initial diagnosis and related to that, the number of clear scans between initial diagnosis and recurrence. Partners of patients

who perceived that treatment for the primary tumour had been a success and who perceived the possibility of cancer coming back as low, seemed to be more shocked on hearing the news. Equally, partners saw patients' regaining of physical strength and returning to work following the initial treatment as reassuring, which also seemed to contribute to a feeling of surprise when recurrence was diagnosed. Time since the initial diagnosis may have been an important factor as the partners of patients who experienced a longer time period between the initial and second diagnosis and who had clear scans in between these times seemed to be more shocked. Hearing that the patient's cancer had metastasised following a number of clear scans was particularly difficult. In contrast, a shorter time period between initial diagnosis and news of recurrence brought, to a certain extent, a feeling of enduring suffering, with little respite between the end of the initial and the current treatment. For one partner, the knowledge and awareness of the possibility of cancer coming back meant that the diagnosis of recurrence was in fact less shocking than the initial news. To date, there has been limited evidence on how these factors may impact on feelings experienced by partners at the time of recurrence. Previous studies looking at the experiences of partners following initial diagnosis have highlighted that the time following the end of the initial treatment can be of significance. It seems that shortly following the end of initial treatment, some partners were as worried about the illness and future prognosis as the patients (Persson et al., 2004) or were even more worried (Johansson et al., 2014), and monitoring the disease was found to be an important aspect of managing uncertainty about the future. However, while these studies show how some of the described factors were perceived by partners at the time of and following the initial diagnosis, an understanding of how these factors play a role for partners at the time of recurrence has previously been poorly described. Some factors, such as perceptions of the success of primary treatment or the length of time between the initial diagnosis and recurrence were described previously in studies exploring patients' rather than partners' experience of recurrence (Elit et al., 2010, Mahon and Casperson, 1997, Sarenmaln et al., 2009). The current study highlights that it is important to consider how information about the prognosis and the effectiveness of treatment is presented to partners alongside the patients.

Following the diagnosis of recurrence, partners need to deal with considerable uncertainty related to the effectiveness of treatment. It was highlighted in the current study that while all treatment options brought a certain degree of uncertainty, there were differences between how chemotherapy and surgery were perceived by partners. This seemed to be related to the aim of the treatment, namely whether it was possible to achieve remission again versus merely stopping the disease progression. Partners described the importance of the patient being offered surgery and the hope that it brought. Partners perceived this option as being “given a chance”, which was magnified by the fact that this was the treatment offered following the initial diagnosis. This perception seemed to be encouraged by health care professionals as well, who also presented surgery as facilitating hope for an extended future. In contrast, partners perceived chemotherapy as creating greater uncertainty for patients’ chances of survival, which seemed to be related to the fact that it was from the outset presented by health care professionals as a less successful option.

Uncertainty related to potential outcomes of treatment and subsequently the future has also been highlighted in previous studies. The majority of evidence comes from studies on the experiences of partners diagnosed with advanced colorectal cancer from the outset, which described that partners often struggled to make plans as they waited to see how the patient would respond to treatment. This uncertainty seemed to be balanced with hope for other options to work in the future (Sjolander et al., 2011, Sjövall et al., 2011). However, while the studies show some similarities between partners of patients with advanced bowel cancer and cancer recurrence, they also highlight a number of differences. The current study demonstrates that once again, previous experiences of cancer treatment seemed to be of significance, as familiarity of the treatment such as surgery provided some reassurance for partners, while introducing a new treatment such as chemotherapy precipitated the loss of hope. One study exploring the experiences of partners of patients with cancer recurrence other than colorectal cancer also highlighted the uncertainty related to potential outcomes of treatment (Chekryn, 1984), but lacked an in depth exploration of what different treatment options meant for partners. In contrast, this study highlights the complexity of the uncertainty which

partners faced. This has been shown to be of importance in relation to the experiences of patients with cancer recurrence (Mahon and Casperson, 1997) but has not been previously shown in relation to partners.

Partners also described the physical suffering caused by treatment as an important factor in evaluating the treatment. As a result, side effects following the treatment took on a variety of meanings. Partners of patients who had an operation for recurrence in the liver perceived it as less physically demanding for patients than the operation at the time of initial diagnosis. This in turn also decreased the emotional burden of the treatment on partners and in fact, to some extent it gave partners an impression that the situation was less serious than the initial diagnosis. Similarly, for partners of patients who were receiving chemotherapy, previous experiences of treatment also had a significant impact on how the current chemotherapy regime was perceived. While severe side effects brought questions about the limits to partners' suffering and considerations about the quality versus quantity of life, a lack of side effects, expected because of the experience of initial treatment, made some partners question the effectiveness of the treatment. Previous quantitative studies indicated that the severity of side effects following treatment can have a significant impact on partners' levels of distress, suggesting that physical demands can be an important factor in evaluating the impact of recurrence for partner. The importance of the impact of the treatment and questions related to quality versus quantity of life have been raised previously in the context of palliative care, but mainly from the perspective of patients (Fried and Bradley, 2003). However, this study also highlights that in fact both a lack of side effects as well as severe side effects may change the perception about the severity of the situation for partners. It seems that once again, previous experiences of treatment from the time of the initial diagnosis played a role here in the way partners made sense of the situation.

The treatment options offered to a patient also had an impact on how partners perceived the aim of the scans. Partners of patients who were receiving chemotherapy only were often hoping for lack of disease progression and longer time to live, as possible disease progression was often associated with the approaching death of a patient. Also, partners as well as patients had to wait longer to see if this treatment was able to stop

the disease progression. In contrast, the initial success of the surgery could have been easily evaluated by seeing whether the tumour had been resected. In that context, partners of patients who were offered surgery saw scans as a chance of receiving a reassurance of the diminishing threat of death or even being cured again. Interestingly, for this group of partners, clear scans could not always provide complete reassurance if the patient was experiencing ongoing symptoms. This may be related to the fact that any sign of recurrence could signify a substantial change in prognosis and loss of hope, related to being given a chance when offered surgery. It appears that in the current study, the experiences of partners of patients who had undergone surgery seemed to resemble to some extent their experiences following the initial diagnosis, where the focus was to maintain the period of remission. Studies exploring the experience of follow-up care in colorectal cancer from the perspective of patients and partners suggest that scans were perceived as potentially providing hope for a prolonged future as well as being a threat to it (Persson et al., 2004). A recent systematic review also highlighted that treatment type can have an impact on the severity of fear of cancer recurrence following the initial diagnosis of cancer among patients (Crist and Grunfeld, 2013). More specifically, patients who received chemotherapy experienced more significant fear of recurrence than patients who were offered surgery. The current study highlights that a similar process of evaluation in relation to fear of disease progression seems to take place following recurrence and that it also affects partners.

**6.4.3 Part A-Cross Case Longitudinal Superordinate Theme 2:
“Dealing with loss of their previous life and their partner as they knew them”**

The second Cross Case Longitudinal Superordinate Theme: “*Dealing with loss of their previous life and their partner as they knew them*” describes a variety of changes experienced by partners following a patient’s diagnosis of recurrence. These relate to changes to their previous way of living and closely linked to that, the loss of an important person in their life.

The diagnosis of recurrence is an important point for partners as it often means facing either temporary or permanent losses to their quality of life. If patients suffer physically, it often means that partners have to take on additional caring and domestic responsibilities as the patient is limited in

what they can do. The emotional impact of this is often magnified by the fact that it often means a temporary or ongoing loss of their partner as they know him or her. This is related to either a threat of death indicated by a poor prognosis, or the physical changes experienced by patients. With time, some partners are able to regain their previous rhythm of life and consequently their partner in life, but have to negotiate these changes slowly as the threat of imminent death diminishes. Others struggle to regain their previous ways of living. This is related to a physical deterioration of a patient or the new needs of patient following a diagnosis of recurrence.

As previously described in the Methodology chapter, Table 6.4.3 sets out the Cross Case Longitudinal Superordinate Theme 2 and then, for each partner, their individual within case Longitudinal Superordinate Theme, together with their individual Superordinate Theme at Time 1 and at Time 2, and Subordinate themes identified.

Table 6.4.3 Cross Case Longitudinal Theme 2: Dealing with a loss of their previous life and their partner as they knew them

Cross Case Longitudinal Superordinate Theme 2 :Dealing with loss of their previous life and their partner as they knew them		
<p>Louise: Regaining some normality while facing permanent losses</p> <p>Time 1: Coming to terms to losses of previous quality of life with partner</p> <p>At the time of the first interview, Louise describes a number of changes to her life as a result of her partner's recurrence. She accepts them as part of the new situation, and seems to perceive them as part of caring for her partner. However, she also mourns the losses to her life and describes how adjusting to a new life requires extensive planning.</p> <ul style="list-style-type: none"> ✓ <i>Adjusting to restrictions imposed by bowel movements</i> ✓ <i>Having to plan to be able to partially regain her previous life</i> ✓ <i>Negotiating caring with partner</i> 	<p>Anthony: Leaving the imprisonment of cancer after regaining his partner</p> <p>Time 1: Feeling trapped in a painful cancer world with his partner</p> <p>At the time of the first interview, Anthony describes at length the losses to his previous life as a result of his partner's recurrence. His previous life is lost and a new one seems to revolve around cancer. He feels overwhelmed with his partner's physical suffering as he mourns the loss of a previously capable partner. He feels frustrated and hopeless as he feels he is unable to help his partner.</p> <ul style="list-style-type: none"> ✓ <i>Becoming a prisoner in the cancer world</i> ✓ <i>Feeling overwhelmed by the never-ending suffering of his partner</i> ✓ <i>Questioning the fairness of the dramatic decline of his partner</i> ✓ <i>Feeling responsible for his partner's physical suffering</i> 	<p>Alan: Enjoying regaining his previous routines</p> <p>Time 1: Coming to terms with the threat to his previous life</p> <p>At the time of the first interview, Alan describes his struggles to come to terms with the threat of losing his partner. This is also visible in his family's reaction, where the family's previous rhythm of life seems to be suspended. He also describes the practical challenges as a result of his partner's diagnosis, which seem to decrease with time as she is not suffering from severe side effects.</p> <ul style="list-style-type: none"> ✓ <i>Having to adjust to the increase in responsibility following the news</i> ✓ <i>Fearing losing his partner in life prematurely following the news</i> ✓ <i>Getting the family on alert</i>

Table 6.4.3 Continued Cross Case Longitudinal Theme 2: Dealing with a loss of their previous life and their partner as they knew them

Cross Case Longitudinal Superordinate Theme 2 :Dealing with loss of their previous life and their partner as they knew them		
<p>Time 2: Regaining some normality of her life</p> <p>Similarly to the first interview, Louise describes the ongoing efforts to accommodate her partner's needs and the impact of that on her life. She still seems to perceive trying to control his bowel problems as a joint activity. However, in contrast to the first interview she identifies the limitations to that approach as she sometimes struggles to relinquish control over her partner's choices.</p> <ul style="list-style-type: none"> ✓ <i>Making adjustments to her life to accommodate partner's needs</i> ✓ <i>Joining in to support partner with bowel problems</i> ✓ <i>Struggling to relinquish control over partner's choices</i> 	<p>Time 2: Slowly regaining his partner and joy for life</p> <p>By the time of the second interview, Anthony seems to be overjoyed with his partner's progress and wants to organise his day around his partner's needs. His account seems to mainly focus on his partner slowly regaining physical strength. However, his partner's recovery means that he also realises the need to stop being overprotective.</p> <ul style="list-style-type: none"> ✓ <i>Trying to lessen the suffering by arranging his day around his partner's needs</i> ✓ <i>Trying to establish a new routine</i> ✓ <i>Slowly leaving the "black period" behind</i> 	<p>Time 2: Enjoying the temporary return of his previous life</p> <p>By the time of the second time, the feeling of urgency is gone and Alan focuses on the decreasing immediacy of the threat of his partner's death. He seems to enjoy the return to previous ways of sharing the household chores between his partner and himself. This is again also reflected in the wider family dynamic, with a return to previous rhythms of family life.</p> <ul style="list-style-type: none"> ✓ <i>Celebrating his partner being able to enjoy day-to-day life</i> ✓ <i>Sharing day-to-day chores lessening the impact</i> ✓ <i>Physical symptoms disrupting normality of the day-to-day</i> ✓ <i>Decreasing threat of death changing the family dynamic</i>

Table 6.4.3 Continued Cross Case Longitudinal Theme 2: Dealing with a loss of their previous life and their partner as they knew them

Cross Case Longitudinal Superordinate Theme 2 :Dealing with loss of their previous life and their partner as they knew them	
<p>Victoria: Losing her partner to the relentlessness of cancer reality</p> <p>Time 1: Struggling to adjust to a new reality with her partner</p> <p>At the time of the first interview Victoria describes the extent of changes to her life following her partner’s diagnosis of recurrence. She initially resists giving up her work as it allows time away from the reality of cancer. Following her decision to have a break from work, she feels overwhelmed with caring responsibilities towards her partner. She reflects on the dramatic changes to her partner as he becomes very fragile, which she struggles to accept.</p> <ul style="list-style-type: none"> ✓ <i>Holding on to professional life initially as part of normality</i> ✓ <i>Feeling trapped in cancer world</i> ✓ <i>Negotiating parenthood in the reality of recurrence</i> ✓ <i>Struggling with regaining and losing a partner</i> ✓ <i>Seeing the transition from capable to fragile partner bringing distress</i> 	<p>Michael: Slowly embracing becoming part of cancer reality</p> <p>Time 1: Facing the transformation of his partner and life</p> <p>At the time of the first interview, Michael describes both positive and negative changes to his partner’s lifestyle, following the diagnosis of recurrence. He seems to struggle to accept some of the changes but decides to embrace them to maintain closeness in his relationship. He also describes changes to both his and his partner’s standard of living, while feeling uncertain about being able to regain them.</p> <ul style="list-style-type: none"> ✓ <i>Coming to terms with the dramatic changes to his partner</i> ✓ <i>Trying to be part of his partner’s new regime to maintain closeness</i> ✓ <i>Facing difficulties in regaining previous patterns of work following diagnosis</i>

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<p>Time 2: Previous life being taken over by cancer</p> <p>By the time of the second interview, Victoria’s life seems to be taken over by cancer as she feels unable to engage with non-cancer related activities. As her partner’s treatment regime becomes more demanding, she questions the limits to his suffering. She also describes how changes to her partner mean that he is no longer able to participate in family life.</p> <ul style="list-style-type: none"> ✓ <i>Struggling to deal with work-related issues among cancer-related issues</i> ✓ <i>Struggling with a slow loss of partner’s recovery periods</i> ✓ <i>Seeing the increasing decline of her partner over time due to treatment</i> ✓ <i>Routine of deterioration and recovery becoming normality for children</i> 	<p>Time 2: Being part of cancer community as a new normal</p> <p>By the time of the second interview, Michael seems to be more accepting of changes to his partner and is happy to facilitate meeting his partner’s needs. However, he finds his partner’s involvement with cancer charities overwhelming at times, as it seems to be a reminder of his partner’s situation as well. Despite these challenges, financial concerns seem to remain priority for him.</p> <ul style="list-style-type: none"> ✓ <i>Accepting being in the background to facilitate his partner’s needs</i> ✓ <i>Experiencing intermittent moments of being overwhelmed with cancer reality</i> ✓ <i>Seeing financial concerns as a priority</i>

All participants seem to experience changes to their life as well as their relationship with a patient. For Louise this seems to be related to her partner's difficulties with bowel movements which cause some losses to their day-to-day life, as well as changes to the dynamics of their relationship. In contrast, for Anthony and Alan, the changes to their lives are related to the emotional impact of their partner receiving a poor prognosis and additionally for Anthony, the severe physical suffering of his partner. However, the lessening threat of immediate loss of a partner means that with time they are able to regain to some extent the rhythm of their previous life and emotional balance. In contrast, Victoria and Michael, although for different reasons, experience ongoing changes to their lives. Victoria, similarly to Anthony, needs to face the severe physical suffering of her partner and consequently substantial changes to both her quality of life and her relationship. Unlike Anthony, these losses are however permanent. Finally, Michael also experiences substantial changes in his relationship with his partner, which are related to her newly emerging needs following a diagnosis of recurrence.

At the time of the first interview, Louise's partner has had one clear scan and he seems to be suffering mainly from unpredictable bowel movements. In the context of unpredictable bowel movements, Louise faces a number of changes to her life. Here we can see the loss of previous way of socialising: going out. She seems to empathise with her partner and want him to feel comfortable and as a result his bowel problems are managed at home, which seems to create a safe space. As she goes on, she seems to acknowledge the loss of that aspect of her social life and in fact she admits that she misses it. However, the change seems to come easily to her and she is willing to give it up readily as she thinks about the impact of going out on her partner:

Yes, well we'd rather have friends come round to us because the only thing that does impact us is X [patient]'s bowels. So he would, both of us really, would rather be in our own place and have friends come to visit us, rather than, I get embarrassed for him as well if we were out somewhere, you know. So that has, we used to go out for meals and that, and I do miss that but, well we've just changed our lifestyle, that's basically what we do. I'm so easy to please, you know, we've just changed our lifestyle.

As she continues in the interview, it is revealed though that while Louise seems to deal with the losses to her previous lifestyle, we can see that it is also challenging. She starts with acknowledging that it is “annoying” which she immediately retracts. This may suggest the difficulty of expressing the negative feelings caused by the changes and the feeling of being responsible for meeting her partner’s rather than her needs. While some activities are still possible, they are not able to completely replace the clearly previously enjoyed activity of eating out. The quality of her previous life is gone and in fact, Louise seems to reassure herself by stating her belief that she is coping:

It is annoying, not annoying, it is, it impacts sometimes on what we can do and where we can go. I mean we don't go out for a meal because that's a no, not now, unless, well, you know, unless he took Imodium before we went, I mean a meal in a restaurant. We have been to friends and things like that. But no, it obviously has impacted on us, it's not the same as it used to be and it's just, you just have to alter your lifestyle, you know. I think I'm coping with it OK.

Louise’s partner, Chris, does not seem to focus on the potentially negative impact of his unpredictable bowel movements on Louise. He seems to embrace her willingness to help him in managing the effects of the treatment on a day-to-day basis. The love for her husband seems to fuel Louise’s willingness to let go of their previous life. She feels reluctant to discuss her needs and focuses on the importance of her relationship with her partner. However, it may be that by accepting this sacrifice she rejects the image of the person who she thinks may be associated with a person who does not in fact accept the losses. That image may be more difficult to accept and it drives her willingness to see it as minor inconvenience rather than a sacrifice.

I suppose, it doesn't bother me that we're not going away on holiday or anything like that. We do, do things, I'm not that sort of person that says, oh I don't know about this, I'm not able to go on holiday, you know, or anything like that. No, I love my husband to bits and we're just coping between us.

Louise seems to be involved in caring for her partner in a number of aspects. Here, we can see how food seems to be an important part of this. The trial and error approach is challenging as it sometimes results in sudden bowel movements, which Louise feels responsible for:

The day to day, it's difficult to know what to give him to eat, food, it is difficult. Because if you make a mistake and he has something he shouldn't have, then that will go straight through him and that's not nice, you know. I think the impact really is just basically food and knowing what he can eat and what he can't eat.

At the time of the second interview, unpredictable bowel movements seem to be an ongoing concern and life seems to revolve around them. Similarly to the first interview, Louise seems to adjust to the changes to her day-to-day life to accommodate her partner's needs. Here, we can see the process of decision making regarding holidays abroad. This does not seem to come easily as both Louise and her partner seems to consider the potential advantages and disadvantages of going. The decision seems to be instigated by Louise who does not see her partner as ready for this activity. Not being able to control his bowel movements as well as an inappropriate diet seem to act as barriers again for both Louise and her partner. She seems to quickly try to minimise the impact of that by thinking about the possibilities which are available to them. As the holidays abroad used to be an important part of their lives, planning even shorter trips abroad seems to be very important for Louise. This makes her feel "quite happy":

I mean our friends wanted us to go to X [city] with them in August and we hummed and hummed about it and X [patient] said, no. He said, oh, I said, I don't think you're up to it. He said, no I'm not up to it, not going over there. Two things, the flight, which is six and a half hours, and the food is absolutely gorgeous over there and it is rich food. And he knows that he wouldn't be able to eat the meals over there like he did before, he doesn't really want to spoil it for anybody else. And sometimes he's not that sensible because if we did go there, he might eat something, oh that will be alright, and then he'd have a really, really bad night, you know. But there are other places we can go, I mean we haven't tried to go abroad yet. But there are

definitely places you can just get on a plane for an hour isn't there, you know. But we're quite happy, we're quite happy, we've got our different trips to go to, you know.

The unpredictable bowel movements seem to be still a major concern for Louise and have clearly a significant emotional impact on her. It seems that leaving the security of the home generates huge anxiety, even though it happens on rare occasions. The frequency of the bowel movements makes the diagnosis visible in the public space, which both of them find uncomfortable. Again, Louise seems to empathise with her partner and this fuels her willingness to accept the losses to their social life:

It's always a worry if we should go out for the evening, it's normally only to somebody's house or we go to the pub quiz once a month, and he gets a bit stressful if, for example, we go to the pub quiz and he, oh my bowels are going to work. And he doesn't like getting up and going out and coming back and then, like that, you know. That's embarrassing for him, although everybody understands, that's embarrassing for him. [...] I get worried about him, I feel for him. I don't get stressed but I get, I'm just worried.

Similarly to the initial interview, Louise takes responsibility for providing the best care to her partner. Knowledge about the medication as well as strategies for dealing with bowel movements are shared between Louise and her partner. However, we can see that with time it is also difficult for her to relinquish control in certain aspects. Here, Louise recalls a difficult situation which demonstrates the challenges of caring for her partner. While she seems to describe a specific situation, there is a suggestion that this is in fact "a habit". As the unpredictable movements are clearly a problem for her partner, the perceived carelessness of her partner as directly contributing to the problem is very difficult to accept for her. Eating together seems to be a controlled situation, which other people disrupt. Again, the responsibility for her partner's well-being and seeing recovery as a joint responsibility seems to create difficulties in relinquishing control over her partner's eating. While seeing her partner suffer is difficult, any suffering generated by her partner himself is even more challenging to face. While she wants to give her partner the control over his eating, envisaging his future suffering seems to be the focus of her thinking. It seems that she is

considering what she should do almost as she speaks and making a decision to take a new approach:

I must get out of the habit of doing it but X [patient] will look at the menu and he said what he wanted and I said, do you think you should eat that? And as soon as I said that, then he got a little bit funny and he said, oh you choose what I'm going to eat then. Although I didn't, I didn't mean it, I didn't want to choose what he wanted to eat, he could choose for himself, but sometimes when he chooses something I'll be thinking, you shouldn't have that. But I should just let him get on with it really shouldn't I, you know. Yes, I must take a step backwards and just let him eat what he wants to eat and then if it goes through him or something then, you know.

Louise's partner does not mention this as a problem in his interview. It might be that he realises the extent of support received from his partner, which in turn balances the feelings of overprotection, if there are any.

While the changes to Louise's life seem to be related mainly to her partner's problems with unpredictable bowel movements, Anthony initially faces a number of wide-ranging problems. As his partner is initially facing a poor prognosis and is suffering physically, we can see the overwhelming impact of recurrence on Anthony. This seems to be related to the loss of his previous life as well as his partner. He seems to be, as described by him, trapped physically and mentally in the world of cancer. Doing voluntary work used to bring some respite for him and brought to him a feeling of belonging to the non-cancer world. Now, the inability to participate in activities enjoyed by other people seems to magnify his suffering and becomes a "chore". The suffering of his partner seems to impose numerous limitations on his life and leads to the loss of previous activities. This is, in Anthony's opinion, in striking contrast to other people's lives and a result brings severe suffering:

I'm in a very dark lonely place, and the only time I get out of the house, I work for, well volunteer for the X [charity's name] two days a week.[...] I can go and meet normal people, but even that's becoming a chore, because people going on holidays, they're going

for days out, they've been to restaurants, that's normality. We can't even contemplate a holiday, can't even contemplate a day out, we can't even contemplate going for a meal out, because X [patient] can't leave the house. [...] It goes round and round, the house is becoming a prison.

The numerous complications and side effects Anthony's partner suffers from show the severity of the situation and the difficulty in adjusting to that for him. The fragility of his partner is revealed here with the loss of her capable body. The relentlessness of partner's suffering is overwhelming and in fact, becomes too much for him. The desire for the hastened death of his partner is what he seems to wish for:

I can live in hope that we can see light at the end of this very long tunnel, sometime she's going to run off and there's a good conclusion to this hell that we've been gone through the last 15 months.

While Anthony's partner, Linda, also describes the losses to her life following the diagnosis, she also tries to focus on the future recovery. The extent of despair is much more visible in Anthony's interview who does not have hope for the future, and the challenge of caring for Linda becomes unbearable. She seems to understand his suffering as she describes his frustrations with his perceived inability to help her. The dramatic decline of his partner's health and a loss of the partner he has known bring feelings of loneliness. He seems to be longing for the spouse he has already lost as she is no longer the way she always used to be. The contrast between his partner as she was, who embraced a healthy lifestyle, and the person who he sees today, magnifies the distress of the situation. The energy and limitless resources of his partner are replaced by a person struggling to meet her basic needs:

It was devastating, because X [patient], we know her in the family as like a little bumblebee, she never sit down, she had all the right food, she ate salads every day, lots of water, exercise, we went for walks every day, and to see somebody you loved for 44 years be almost wiped away in front of your eyes, wasn't able to help herself to the basics in life.

His attempts to ease his partner's suffering by caring for her are also difficult. Here, providing good quality food becomes an unbearable reminder of the hopelessness of the situation for Anthony. As his partner is not able to eat, he feels frustrated with the lack of solutions. The temporary hopes for improvement the next day diminish very quickly and in fact the relentlessness of the situation seems to question his limits of being able to continue to live. His main focus seems to be on Linda's recovery, with his needs being in the background:

I can see her draining out of her face, the colour in her face, and just go back to bed, lie down, and you think well what the hell have I bothered for, you've got washing up, get rid of the food that was wasted, I think well, let's hope for a better day tomorrow. Tomorrow never comes, you keep wishing, you end up wishing your life away, and towards the end of the day I wish it was the end, the last day of the world I see. I just feel the end of my tether right now

By the time of the second interview, Anthony's partner has recovered physically from the operation and has had one clear scan. Throughout this interview, Anthony seems to reflect on the changes which he has experienced in the meantime in relation to his partner, his life as well as his own feelings. He seems to acknowledge the feelings of despair and frustration which he experienced before. However, some of these feelings do not seem to have gone away yet as he seems to switch between present and past:

There were occasions when just feel as a husband, just sometimes one felt absolutely useless, and that could be turned into frustration, anger, because there's nothing more I can do, except do one's best and endeavour to make X [patient] as comfortable as possible

We can see the fragility of Anthony's well-being and the situation here as well. While he is willing to care for his wife, he still seems to see his future as dependent on his partner:

I always felt that if anything occurred to X [patient], that I wasn't prepared to go much further without her, and I still feel the same way. If anything happens to X [patient]. [...] I have no idea where I'd

be today, and if anything occurred in the future, our future is the future.

However, apart from these concerns, as a result of his partner's physical recovery following the operation, a new routine starts to be established. To some extent it is the return of normality, but we can also see a new dynamic of the relationship. Similarly to Louise, Anthony and his partner seem to negotiate sharing the chores, and the previous way of providing comprehensive care seems to slowly disappear. We can see the difficulty of that for Anthony as he has to relinquish control and let go of constant worry, which has dominated his thinking previously:

But we go about our normal, we go about the house quite normally really. We do as much as we can between us, and anything that I think, giving X [patient] the freedom to do what she wishes, with the constraints that I hope she doesn't hurt herself, so I'm probably overprotective, but she normally tells me when I'm being overprotective.

While Anthony seems to acknowledge the fact that he may be overprotective towards Linda, she focuses on this issue throughout her second interview. She describes her need to return to previous activities and to reject the sick role in the family. This is an important step in not only facilitating recovery but also rebuilding their previous relationship.

Similarly to Anthony, the impact of the recurrence on Alan is related to prognosis and, with time, to a lesser extent the treatment. While Alan's partner was going through the chemotherapy following the recurrence, she was not initially able to contribute to the running of the household, which they used to do together. We can see reluctance from Alan to mention this, as it may suggest that he wants to shift the focus of the impact on himself. However, it seems that the practical impact is as difficult to deal with as the emotional one:

So there was that impact on me. Yes, there was a lot more work I had to do in the house. It sounds a bit selfish possibly this, but if you're talking about real practical impact of it, rather than sort of necessarily the emotional impact, which was that suddenly I think, I had to come to cope with.

Similarly to Anthony, the threat of the loss of his partner is clearly overwhelming and comes as a surprise. We can see the multi-layered impact of the potential meaning of the diagnosis for Alan. The diagnosis seems to be against the expectations of the course of the life he has previously envisaged. The premature death of his wife also means facing older age alone, which is challenging. Being alone does not only mean being lonely but also losing a member of a team who is able to share the responsibilities of day-to-day life:

The whole news was a shock to me. I'm ten years older than my wife, it never ever crossed my mind that I would outlive her. Suddenly, this was a reality, if you like. I could be me on my own, you know, I'd never dreamed that I would be a widower within a space of time, you know, this was a lot, you could say was selfishly, if you like, I was thinking, what on earth am I going to do? Because, although I was saying I do a lot of the cooking, we are a team and I lean on her for a lot, you know.

We can see the impact of the news on the rhythm of daily life. In the uncertainty of the future, one of Alan's sons started coming home for a few days a month. The support from his son's workplace seems to be appreciated by Alan:

In fact he's been, they were very good to him at work. They sort of said, you know, take all the time off you want. And he's been coming up for a couple of days each month, because he has a job where it's possible for him to come up home and work on the computer from home, whilst still making some contribution. So they've been very good.

At the time of the second interview, Alan seems to be pleased about the fact that chemotherapy for the recurrence is less demanding on his partner than initially envisaged. In turn, the treatment also seems to have less impact on day-to-day life. As he continues to describe, we can see the positive impact of his partner being able to participate in day-to-day life. Her ability to undertake these activities seems to reassure Alan that she feels well. Alan's partner's physical well-being also allows sharing of the responsibilities of day-to-day life, which seem to lessen the impact for Alan. Similarly to in his first interview, Alan seems to feel reluctant to mention his

partner's ability to help in managing the household as it may suggest that he focuses only on himself and his needs. Regardless, the practical help he receives seems important to Alan, as it allows him to continue to work, while his wife can take care of the household:

Well it's, on a practical day to day basis, she's able to do the, I mean it sounds a bit basic, she's able to keep the house clean, work in the garden. I always tend to do most of the cooking anyway generally, always did, before or after. So yes, day to day, things are functioning fine. She has, as I say, she has the odd off days but yes, you know, she's well enough to do all these things, take an interest in the garden and all the rest of it. So that's how things work out. So I continue to work, yes it's OK.

In fact, the main worry seems to be the potential inability of his partner to share the responsibility of running the household. As Alan is determined to continue working, having to manage both work and home affairs would be in fact "unbearable". It may be that it is not the increase of chores which would become "unbearable", but rather what the situation could potentially represent – his partner approaching death:

It would be unbearable [...] when X [patient] couldn't do anything. Shall we say, where I had to do, as I say, I do, I work a full week, I do the cooking and most of the buying of the food. X [patient] does the, keeps the house clean, does the laundry and things like this.

Johanna also describes a "bad day" when she suffers from physical symptoms. This interpretation is not only related to her physical suffering and inability to participate in daily activities but is also as reminder of the severity of the situation. Once again, there seems to be absence of talk about death in Alan's account, thus creating tensions in the relationship.

We can see here how only intermittent physical symptoms seem to disrupt normal day-to-day life. While a "bad day" can bring physical suffering, this does not last long and seems to be an exception rather than the normality for Alan. Good days allow his partner to undertake activities as before the recurrence of cancer and this seems to be reassuring. However, we can see that maybe in fact a "bad day" is not rare as such but it is familiar and consequently, represents less threat. As it is also managed, it does not bring major concerns and allows Alan to continue with his activities:

Well if she's having a bad day she'd just be sort of lying down, will lie down there and it's not quite clear, I mean she wasn't so good a couple of days ago. [...] So yes, that's the way it is, has the odd off day but generally, it's OK and able to function, able to go out, drive. [...] I've got used to having a lot of these bad days over several years, you know, she just takes her tablets and most of the time it will pass, you know, it will pass. It's usually like infections, like water infections that she has. Takes the tablets and that's it really. So it doesn't really, I just go on working.

Clear scans and, as a result, the decreasing threat of death also seem to change a dynamic in the family. Alan's son's visits take on a different meaning: they are no longer possible goodbyes but part of family life. The well-being of family members is improved and Alan seems to enjoy that "everybody is calmer":

Things are much more relaxed now. He [son] doesn't feel he has to come home every month and treating as if, you know, every month is the last month that he might see his mother. Things are much more relaxed now and I mean he was up, he just, he's been up a week or two ago and he's probably coming up, but it's not like that anymore.

In contrast, while Johanna also describes her hope for chemotherapy continuing working, she also starts thinking about possibility of dying. This seems to be absent from Alan's interview and may reflect his approach in dealing with the distressing nature of the situation.

While Louise, Anthony and Alan were able to restore at least some temporary balance to their lives and their relationships, Victoria and Michael do not seem to regain their previous lives, but face dramatic changes.

Victoria also describes significant changes to her partner and consequently her life, which are, similarly to the initial experiences of Anthony and Alan, related to the ongoing treatment regime of her partner. At time of the first interview, Victoria describes her experience of the transition from professional life to becoming a carer for her partner. Following the initial diagnosis, Victoria was still working. However, after her partner's surgery

for recurrence, she makes a decision to give up working. This decision is clearly difficult for her, as working seems to represent normality for her, to which she is holding on. Stopping working represents the end of an important phase and to some extent, giving up her own needs and the hesitance to give in is visible here. Despite being encouraged by people around her and in fact, "everybody", she refrains from doing that for some time:

Well I did, everybody kept saying, you know, the GP was saying, I can sign you off, you know, do you want to do that? And I sort of resisted, for quite a long time because I thought I know as soon as I stop that that will be it, and I just kept sort of going to work thinking I can do this, I'm alright, I can, you know, I can manage. But it has been a lot better since I've been at home.

However, even with not working, the chores seem to fill in every day, not allowing a respite. Two worlds of cancer and non-cancer seem to be running parallel to each other and Victoria is not able to belong to both. The world of cancer seems to be filled with chores while the non-cancer world allows spending quality time with people and a respite. Like Anthony, Victoria seems to have become an observer to the non-cancer world: the quality of time spent with people is different and time doing chores seems to be slipping away:

I feel like I'm just pedalling along in the background, and everybody else is kind of moving around and I'm not really joining in as much as I used to. With children and you know other people.

The relentlessness of chores also has an impact on her feelings about her ability to be a good mother. As her partner is not able to help her, she needs to take care of the day-to-day running of the household. She describes how the overwhelming nature of chores does not allow the mental space to attend to her children as she would like to. While Victoria seems to realise the impact of a new family dynamic on her children, she is unsure of the extent of her children's awareness of the situation. Preserving normality is seen as a buffer for the emotional impact of day-to-day tensions caused by the diagnosis:

Try and make things as normal as possible for the children, because they are kind of aware of the emotional, you know, ups and downs, but they don't and they see us getting quite impatient with them and sometimes they don't realise why, and other times they, you don't know how much they pick up on really, and how much it affects them but, it doesn't really seem fair on them either.

Different levels in her partner's physical well-being allow different rhythms of family life. Her partner "feeling better" allows her to regain help in the day-to-day running of the household. It does not mean a reversal of roles, but rather lessens the responsibility for Victoria. It also seems to be an implicit reminder of her previous life with her partner. Intermittent moments of her partner feeling "really OK" allow her to enjoy family life, away from the chores. However, we can see the fragility of these moments as they need to be carefully executed to accommodate her partner's physical limitations. This seems difficult to deal with for Victoria and we can see to some extent her impatience with her partner here that even good moments have their very limited boundaries:

Well I guess the good days are when X [patient] feeling better and he's a bit more like himself, you know, and he can actually help with amusing the kids or help me do the cooking. If he is feeling really OK, then we will go and do something, we'll go out or we'll go somewhere with the kids and you know, but then we have to be careful not to overdo it, because he will end up feeling really exhausted and getting really grumpy then.

James, Victoria's partner, also realises the impact of his physical limitations on Victoria and his family. He describes his feelings of becoming a burden to his family and his struggles to find ways in minimise the burden. He tries to talk to his partner as a way of helping her; however, she finds it difficult to share her feelings, which in turn seems to magnify James' perception of lack of reciprocity in the relationship.

The relentlessness of the situation is also magnified by her partner's ongoing physical suffering, which is difficult to accept for Victoria. Ongoing side effects and his decline over time make her question the limits to his suffering. Side effects following recent radiotherapy treatment are now starting to appear and seem to trigger her thinking about the relentlessness

of the treatment. When talking about continuing treatment she seems to present her partner's rather her own view. It may be that verbalising these thoughts is too difficult for her:

I've really noticed a difference over the last few months, how his tiredness has just really debilitating really, where he's in bed quite a lot. So you've got that sort of balance of, he wants to keep going having the chemo, obviously, but you don't want it to affect your quality of life and being able to do things, it's no good if he's just in bed for the whole time.

While the impact of her partner's treatment is visible in the diminished quality of their day-to-day living, similarly to Anthony, it also represents the loss of the previous relationship with a capable partner. The respite from treatment cycles does not allow the return of the old partner. Both Anthony and Victoria compare their old partner, known to them as enjoying numerous activities and not previously suffering from any medical complaints, with a person constantly taking tablets and facing possible death. The break from treatment does not bring back the old partner as he is never really as he used to be:

He takes so many tablets every day, even when he's not having his chemo to manage all the side effects, that that's also quite difficult, because when you've known somebody beforehand, and you know, he never ever went to the doctors for anything, he'd never ever go to the GP, he wasn't ill ever, and then for this to happen is completely a major shock. He used to, you know, cycle and run, and do all that stuff. Now he says he feels like he's just like an old person because of all the drugs and things he has to take.

At the time of the second interview, Victoria continues to struggle with numerous challenges, including work, the new treatment regimen of her partner and increasing chores. Her life seems to revolve completely around James' illness and consequently needs, with her problems having to blend into a background. While initially Victoria's work has been supportive of her going on sick leave, she is now faced with the uncertainty of her situation. Her pay is going to be suspended and now she needs to deal with this as well. There seems to be some support for her to deal with this, however, being overwhelmed with numerous responsibilities, there does not seem to

be time to deal with employment amongst other issues. She sees the procedures which her employer has to go through as adding to the burden of her situation and the uncertainty of the situation seems to be more challenging than an actual possibility of job loss. Since the return to work is not perceived as an option at the moment, there does not seem to be any space to think about work-related issues. In addition, having children at home puts constraints on conversations with her employer as it is difficult to speak openly:

When they ring and you've got children here and you can't really speak to them and, yeah, it's quite difficult and they say oh, can we come out to see you, you know, you never get a chance to sort of, you know, arrange all of that stuff. So in my mind I think it would be easier if they just said we want to terminate your contract, here's some money and go away kind of thing. I think that would be probably the best all round really, so, that would be my preference.

She also faces new challenges related to her partner's new treatment regime. The first cycle of the new treatment seems to raise a number of questions for Victoria about the limits to her and her partner's suffering. The importance of a break, even a short one, is very important for both of them, as it allows them to gather enough physical and emotional resources to endure another cycle. The period in which she was able to have some respite and share the burden of the day-to-day running of the house with her partner is gone, which is challenging. Even though this help was mainly related to "simple things", it is not possible any more. As a result, she seems to be left with doing everything on her own, with her needs being neglected:

Because he's not been able to do anything really, he's not been feeling well enough to do like simple things that he would do when he was feeling well, on his good weeks, so it's been a bit of a slog really.

Regardless of the impact of the loss of recovery periods on her, she also grieves the impact of this on her partner himself. She acknowledges the loss of the recovery period from the treatment on her partner and describes how the good days have been replaced by ongoing side effects and suffering. We can see the severity of the side effects as well when Victoria

describes them as “not illnesses” but resembling illnesses. She tries to understand and empathise with partner’s suffering by recalling periods of her own suffering. These are only experiences by proxy and she seems to realise that she is not able to fully understand the impact of the suffering on her partner:

There’s just endless things that he never had before, but they seem to be more of a permanent fixture all the time now, and that’s making, you know, you know yourself what it’s like when you don’t feel well, but to have that every day, all the time feeling unwell, must just be completely draining, to never get any good days. It just kind of, don’t know, it’s really demotivating isn’t it, thinking well I’m taking all these drugs but I’m getting all these other side effects. So that’s quite, that’s the most challenging thing.

While at the time of the first interview, Victoria seems to be concerned about the children’s adjustment to the situation, the treatment regime now becomes almost a routine for them. We can see the familiarity of the situation for Victoria as well who seems to describe the situation in language used when talking to children. The familiarity of the suffering means that “daddy” is not available following the treatment and the routine of going to the grandparents becomes a new normal. This understanding is also shared by James, which highlights that talking about the impact of illness on children is one of the few topics they discuss together:

They know like the cycle of events as well, you know, that daddy goes to hospital and he has his medicine and then he doesn’t feel well, you know, he’s upstairs and having a lie down. [...] and sometimes when he has been in hospital for his chemo, you know, that night that he is not well, one of them, they sort of take it in turns, will go and stay at grandma’s, just so there’s only one of them here, so it’s a bit quieter, so yeah, they just go to grandma’s, and they will say oh, can I go to grandma’s tonight? So yeah, they are quite familiar with the routine.

At the time of the first interview, we can see how Michael struggles to deal with a variety of changes to his life and to relationship with his partner. The dramatic transformation of his partner seems to have a significant impact

on Michael and his life. While for Louise, Anthony and Victoria, we can see with time an establishment of a new routine in the relationship, for Michael the well-known routines and relationship have been challenged by his partner's new needs and priorities, especially around exercise, which he sees as excessive. The worries about the relationship seem to be fuelled by both his and other people's opinions. He seems to acknowledge that the relationship he used to have might have been a protective one but the changes are nevertheless difficult to accept and he tries to challenge them:

We've been together for 20 years, and I would imagine the majority of time in 20 years, that we're together 24/7, and I think I got very protective probably. It brought us, it brought us closer, but at the same time I think, I spoke to her mother over the weekend, and she said I can see gaps appearing in your relationship, because X [patient] suddenly started, from us being the 24/7 relationship, she started doing all these things, she'll go out, I mean she's walked down here today, and we're about two and a half, three mile away, and it's the third time this week that she's done it, and if I didn't tie her down she'd walk back, but it's uphill, so I said no, you're not, you don't do it.

Kate seems to be aware of the difficulties her partner faces in accepting these changes and she feels guilty about the changes to their relationship. It seems that as a result of the fear of growing apart, Michael tries to be part of the new regime to maintain the relationship with his partner. Here for the first time he seems to express some support for his partner's exercise regime. Undertaking exercise is not easy for him as he is used to gentler activities. It also demands that he changes his previous activities:

I think we're closer, but I think at the same time we, we spend, she's doing all this exercise thing, which I, you know, I'm glad that she's doing it, I started doing it with her, I struggled, so I gave it in, I don't mind walking.

On the other hand, the dramatic transformation following a cancer diagnosis seems to also relate to his partner's improved confidence. The activities previously perceived as unthinkable are now possible and Michael seems to welcome the change in his partner:

In one respect all this has given her, boosted her confidence, and it, it seems odd that an illness like cancer, she's had to have that before it would make her, give her confidence. [...] It's altered her, the last two years she has altered, for the better.

While Kate also describes at length the changes to her lifestyle and the family's attempts to persuade her to minimise these changes, she seems to be unaware of Michael's appreciation of the positive impact of cancer on her confidence levels, as described by Michael.

The diagnosis of recurrence also seems to create changes to their quality of life, including severe financial problems. As his work involves working with his wife, it has also been affected. The loss of their client base, which had already followed the initial diagnosis, seems to be one of the factors contributing to the current financial struggles. However, the diagnosis itself seems to contribute as well. Worries triggered by the news have halted their ability to work and their previous routine has been lost. Their financial struggles seem to trigger drastic measures to meet their financial needs. Here, Michael describes an example of the financial impact when his partner was willing to sacrifice her equipment to be able to lessen the financial struggles. Unlike for his partner, we can see that Michael's decision seems to be motivated by hopes of his partner's being able to return to work, which may underline his hope that his partner regains full health:

No, we were earning, at one stage we were earning a lot of money, that's, that just dropped when X [patient] was taken ill, but photography is her main thing. She's must have 20, 25 thousand pounds worth of photography equipment in the house, that is her main, and things were so bad that she was actually considering selling her photography equipment. I stopped her, because if you're going back I said well you're going to need it, but things were that bad that she was considering selling it.

The return to their previous quality of life is not straightforward, however. His partner's involvement in newly found interests does not allow enough time to restart the business:

It is our intention to go back, if she's got time between doing all the fitness and whatever she's doing, swimming and cycling, but we tend to work a lot in the evenings, be nothing for us to be working at two o'clock in the morning, but now, since she's been diagnosed and since she's had treatment, that's all gone.

At the time of the second interview, the transformation of their relationship seems to continue. Michael seems to accept his role in the background and having his partner's affairs as the focus. Michael supports his partner and her transformation might be what drives this acceptance. We can see an example of this approach here, when Michael tries to help his wife to fulfil her dreams. He seems to think about the losses to his partner's quality of life and almost wants to compensate for them, while also being willing to sacrifice his own needs. In fact, there is a complete lack of focus on his needs, which he seems to accept:

R: That's her biggest thing that she wants to do.

Q: is that something which you want to do as well?

R: I prefer the sun! Yeah, I'd want to, I'd like to go, but it's her big thing, what she wants to do, go photograph the icebergs or something.

As a result of his partner's changes, Michael also becomes a member of the cancer community. While his partner seems to enjoy her newly-found confidence and purpose in life in being an active member of the cancer community, we can see the impact on Michael here. While he seems to be willing to be part of this, we can see that it is also sometimes overwhelming. It seems that the reason for his partner's involvement in these activities, namely her having cancer, is forgotten on day-to-day basis because of the positive changes. However, when it comes to the forefront, it also brings distress:

Well both of our lives revolve, and sometimes, I don't know, I find that occasionally it gets you down. But anyway, I don't mind doing it, but very, very occasionally it does, it does get you down a bit, doesn't get her down, but it gets me down.

Filling days with activity by his partner also seem to bring feelings of loneliness for Michael. As a result of his partner's change, he also spends

time on his own. He seems to find it difficult to acknowledge the feeling of loneliness and he seems to present the worries as being fuelled by the concerns about his partner's safety. His partner also continues to struggle with feeling guilty about changes in her lifestyle, while also enjoying them.

Sometimes it's, like yesterday, yesterday when she was out a long time, if I'm there on my own a long time it's, it does get to me sometimes, like I say, it's more concern and worry that she's OK.

Financial concerns seem to be still at the forefront for Michael and in fact, even amongst all the other changes, they seem to be the most challenging. In the context of his partner's clear scans and recovery, she is no longer entitled to benefits. However, returning to their previous way of working is difficult and creates a concern for Michael:

I think financial I think, I think that's the most challenging at the moment, is, we had, we don't have an awful lot of money, because X [patient] was on Disability Living Allowance which has now stopped because she's not eligible for it.

6.4.4 Part B- Discussion of the Cross Case Superordinate Longitudinal Theme 2: “*Dealing with loss of their previous life and their partner as they knew them*”

The second Cross Case Longitudinal Superordinate Theme: “*Dealing with loss of their previous life and their partner as they knew them*” describes a variety of changes experienced by partners following a patient's diagnosis of recurrence. These seem to relate to changes to previous ways of living as well as the loss of an important person in their life. Firstly, I will describe the burdens related to day-to-day living with losses to their social life and employment as particular examples. I will also explore issues related to the changes to a patient with a particular focus on physical suffering and loss of the partner they used to know.

Treatment regimes can have a profound impact on a patient, which often means for partners increased responsibilities in relation to both the patient as well as in general. In the current study, dealing with what often felt like relentless chores meant that partners often felt isolated and not belonging to the world as they used to do. They often described a lack of time and energy to attend to their own needs as well as other family members.

Additionally, maintaining some normality was very important for one partner with a small family. Partners seemed to experience a variety of emotions as a result of changes to their lives. On one hand, they often felt helpless if they were not able to provide good quality care and questioned the limits to a patient's suffering. Equally, they also felt responsible for or even frustrated either at the situation or in fact at the patient as a result of having to deal with the chores on their own. Patients intermittently feeling better seemed to provide a significant change to the day-to-day rhythms for partners, as it was not only a break from worry about the patient, but also allowed some respite. Previous studies have also indicated that the burden of caring seems to be particularly profound when cancer is advancing (Houldin, 2007, Vivar et al., 2010). However, they often fail to acknowledge potentially difficult emotions (Chekryn, 1984, Vivar et al., 2010) towards the patient generated by trying to provide care. The current study also highlights that the increase of caregiving burden may be related not only to a patient's higher symptom burden but also to prognosis, as partners to patients who perceived the prognosis as poor seemed to be particularly affected as a result of increased chores. Receiving good news seemed to lessen the impact of caring as it took on a different meaning. The current study highlights the importance of recognising that the felt burden of caring should not be considered in isolation but in the context of the perceived prognosis.

Changes to employment are one of the main impacts of cancer on partners. In the current study, participants experienced a variety of changes to their employment. This included taking annual leave to support the patient, suspending the running of their business or even giving up work entirely. As a result, some participants experienced loss of income and consequently, financial difficulties. Some partners found it difficult to adjust to employment-related changes, as they also represented losses to their previous life. Work was not only associated with providing income but was also a reminder of normality and for some, even a respite from providing care. In contrast, brief moments of "normality" provided by part-time volunteering seemed to magnify the suffering as a painful reminder of the permanent losses. Arranging long-term or frequent leave from work could also add to partners' burden, regardless of support from the employer. The issues related to work have been explored to some extent in the

survivorship phase which focused on assessing the costs of caring (e.g Kalayjian, 1989, Hoskins et al., 1996). The impact of recurrence or advanced cancer on a partner's employment situation was explored to a lesser extent. Quantitative studies indicated that caregivers experience changes to their work situation (Wadhwa et al., 2013), with as many as 69% describing missing work because of providing care (Grunfeld et al., 2004). While some qualitative studies highlighted that partners were concerned about their work situations and loss of income (Chekryn, 1984, Houldin, 2007), this was not explored in depth. The current study highlights the complexity of the changes to their work situation and their meaning to partners.

Side effects of the treatment received by patient also meant a number of changes to partners' social life, including limited abilities to socialise and maintain relationships outside families. In the period of active treatment, life seemed to revolve around the patient and partners to patients on ongoing treatment regimes were particularly affected. Activities such as going out were rather limited, but in the context of improving prognosis seemed to have less impact on a partner's well-being. Regardless of that, partners of patients with bowel problems or stomas also faced additional difficulties. As patients had to use toilet facilities on an unpredictable basis, both partners and patients had to make sure that appropriate facilities were available. This was sometimes very challenging, and partners had to face long-lasting changes to their previous lives. Going out could no longer be taken for granted, but required careful planning. In the context of that, some activities were initially ceased and only partially resumed after time. Previous studies of partners of patients with cancer recurrence also highlighted the losses to partners' social lives (Chekryn, 1984). Studies with partners of patients with primary colorectal cancer further highlighted the difficulties caused by bowel problems either as a result of the treatment or a stoma. A recent systematic review on the experiences of partners of patients with a stoma highlighted the challenges experienced by partners in accepting changes to their lives (Danielsen et al., 2013). These were related to patients' difficulties in leaving the house as well as the need for the partner to take on greater responsibility in the household. Other studies at the initial diagnosis of colorectal cancer also highlighted that as the threat of death diminished, the frustration with the stoma seemed to increase (Persson et

al., 2004). This was not the case in this study, as partners to patients with bowel problems seemed to focus on celebrating the diminishing threat of death, and accepted the stoma as a small compromise in relation to the patient being alive. It may be that at the time of recurrence, the threat of death is perceived as more real to partners and in this context, a stoma is seen as a less significant challenge than it was at the time of initial diagnosis, when patients and partners may have been hoping for a cure and a long future together.

The physical changes, particularly loss of appetite or pain as a result of treatment, have had an impact not only on day-to-day life but seemed to be also a reminder of the loss of a previously healthy and capable partner. The contrast between the person the partner used to know and the person the patient became was particularly difficult to accept. Partners' lives seemed to be filled with activities related to caring for their partner. However, despite the busyness of their day-to-day lives, they often felt lonely and experienced a lack of sense of belonging. For some it also meant not only the loss of a capable partner but also having to focus entirely on his or her needs, especially when the patient was suffering from severe side effects. This in turn could bring severe feelings of loneliness, as previous ways of being with a patient were no longer possible and the relationship could no longer fulfil its previous functions. For some partners, this was especially difficult after the realisation that it may not be possible to regain the normality of the relationship following a diagnosis of recurrence. This was related to the terminal diagnosis as well as the physical consequences of the patient's treatment. In contrast, for one partner the transformation seemed to be of a different nature, with the patient making changes to her lifestyle and experiencing a newly-found self-esteem. While these were on the surface positive changes, they still signified a major challenge. As time progressed and the threat of death diminished, at least temporarily, partners found it difficult to stop worrying about the patient and relinquish control. While the patient returning to their activities such as contributing to household chores was welcomed by partners, it also generated a huge amount of anxiety and could even lead to frictions between patients and partners. Partners seemed to acknowledge that they were possibly overprotective by monitoring the patient's activities and diet. The impact of the loss of a partner as the patient knew them has been explored to some

extent by previous studies but only in more general terms. A recent literature review on the impact of caring on partners throughout the illness trajectory indicated that a patient's physical health was one of the primary stressors for partners and could have a major impact on their well-being (Li et al., 2013), while some studies further highlighted that it may be the level of perception of patient dependency or the severity of the treatment on a partner rather than the diagnosis itself which can have the major impact (Nijboer et al., 2001, Compas et al., 1994). However, these studies seemed to focus mainly on the impact of providing care as a result of treatment rather than the consequence of losing a partner they used to know. While there is some description of the impact of loss of the person with whom the partner used to share certain activities, such as running a household, these seemed to be presented in isolation, ignoring the fact that they in fact represent a greater loss, the loss of a person as partners used to know.

6.4.5 Part A-Cross Care Longitudinal Superordinate theme 3: “*Trying to share the burden of caring*”

The Cross Care Longitudinal Superordinate theme 3: “*Trying to share the burden of caring*” describes the attempts of partners to share the day-to-day caring for patients following the diagnosis of recurrence. It describes the challenges they experience in trying to gain support from health care professionals and family and friends, as well as the benefits of that support.

Participants seek and obtain different levels of support from different people at different times in the patient's illness trajectory. Participants who are able to gain some support, either from people within or outside the health care system team, appreciate it as it decreases their feelings of loneliness and can lessen the burden of caring. Also, while for some partners the need for support from health care professionals decreases with time as a result of lesser treatment burden, for others not seeking further formal support is related to a slow disengagement with the health care system. Gaining support is not always possible as partners face some challenges such as communication issues, practical obstacles and a perceived lack of willingness of people to provide support. Often, partners are able to gain support from either health care professionals or family and friends, and rarely from both sources. Unsuccessful attempts in obtaining support seem to magnify partners' distress as it can contribute to the feeling of being the only person providing support to the patient.

As previously described in the Methodology chapter, Table 6.4.5 sets out the Cross Case Longitudinal Superordinate Theme 3 and then, for each partner, their individual within case Longitudinal Superordinate Theme, together with their individual Superordinate Theme at Time 1 and at Time 2, and Subordinate themes identified.

Table 6.4.5 Cross Case Longitudinal Theme 3 Trying to share the burden of caring

Cross Case Longitudinal Superordinate Theme 3: Trying to share the burden of caring		
<p>Louise: Sharing care with others</p> <p>Time 1: Feeling cared for following the news</p> <p>At the time of the first interview, Louise describes the support she received from work as well as the CNS, which she appreciates. While she does not see the need for formal psychological support, she seems to benefit from talking to her friends and family about the situation. However, she also highlights the lack of continuity of care and periods of not feeling sure of the next steps for her partner's care.</p> <ul style="list-style-type: none"> ✓ <i>Appreciating the support from work at times of need</i> ✓ <i>Support from the CNS lessening the anxiety</i> ✓ <i>Feeling "out of the loop"</i> ✓ <i>Feeling supported by friends and family</i> 	<p>Michael: Caring alongside the health care professionals</p> <p>Time 1: <i>Finding support in the health care system</i></p> <p>At the time of the first interview, Michael feels a lack of support from his family and as a result, he seeks support from health care professionals. This seems to meet both his emotional and practical needs. However, he still needs to undertake the role of carer in his relationship with his partner, which he struggles with.</p> <ul style="list-style-type: none"> ✓ <i>Feeling unsupported by the family</i> ✓ <i>Finding a safe haven in healthcare professionals</i> ✓ <i>Struggling to negotiate the boundaries of taking on the role of carer in the relationship</i> 	<p>Anthony: Slowly leaving feelings of abandonment behind</p> <p>Time 1: Feeling abandoned in caring for his partner following the news</p> <p>At the time of the first interview, Anthony feels abandoned by the health care system. He describes his feelings of frustration with not being able to support his wife and not receiving help with that. He also feels abandoned by family and friends, with telephone calls not providing a respite but being a reminder of his partner's suffering.</p> <ul style="list-style-type: none"> ✓ <i>Feeling betrayed by the system bringing overwhelming emotions</i> ✓ <i>Wanting health care professionals' support to ease the responsibility of caring</i> ✓ <i>Feeling overwhelmed by perceived lack of support from people</i>

Table 6.4.5 Continued Cross Case Longitudinal Theme 3: Trying to share the burden of caring

Cross Case Longitudinal Superordinate Theme 3: Trying to share the burden of caring		
<p>Time 2: Valuing support in managing the recurring concerns</p> <p>By the time of the second interview, the way Louise utilises support changes. She seems to seek less support from the CNS, but appreciates its availability. Her feeling of her partner having disjointed care seems to disappear as well.</p> <ul style="list-style-type: none"> ✓ <i>Hoping for continuing support from work</i> ✓ <i>Appreciating availability of continuing support from health care professionals</i> ✓ <i>Feeling of being “out of the loop” diminishing</i> 	<p>Time 2: Confidently utilising support when needed</p> <p>At the time of the second interview, Michael continues to use the CNS as a source of emotional support, while appreciating a good relationship with the GP. However, he starts to identify gaps in the current support system, while giving priority to personal experience of cancer.</p> <ul style="list-style-type: none"> ✓ <i>Appreciating ongoing support from the CNS</i> ✓ <i>Appreciating priority access to the GP</i> ✓ <i>Seeing going through the experience as facilitating provision of support</i> 	<p>Time 2: Slowly regaining trust and faith in support</p> <p>By the time of the second interview, Anthony was able to build a positive relationship with a clinician and as a result he seems to slowly regain trust in the health care system. He also reflects on the support he has received from family and friends. In the context of his wife’s improving prognosis, he seems to perceive it now in a more positive light.</p> <ul style="list-style-type: none"> ✓ <i>Slowly regaining trust in the system</i> ✓ <i>Wanting his partner to receive compassionate care</i> ✓ <i>Valuing support received from people</i>

Table 6.4.5 Continued Cross Case Longitudinal Theme 3: Trying to share the burden of caring

Cross Case Longitudinal Superordinate Theme 3: Trying to share the burden of caring	
<p>Victoria: Leaving formal support behind</p> <p>Time 1: Feeling disappointed with the system</p> <p>At the time of the first interview, Victoria describes at length her disappointment with the support available to patients with bowel cancer. She also highlights how the unpredictable nature of the illness makes it difficult to utilise the support which is available. While she appreciates some ad-hoc support from friends, she also describes the limitations of that support.</p> <ul style="list-style-type: none"> ✓ <i>Being taken by surprise with limited support for colorectal cancer</i> ✓ <i>Struggling to make use of support systems available</i> ✓ <i>Gaining a support network from other people lessening the burden</i> ✓ <i>Not feeling understood by people who are not part of day-to-day life</i> 	<p>Alan: Sharing the feeling of decreasing emergency of the situation with the family</p> <p>Time 1: Slowly letting people in on the potential impact of the recurrence</p> <p>At the time of the first interview, Alan described his initial concerns about having to take on additional responsibilities, which with time decrease due to a less demanding treatment regime. He seems to struggle to discuss his partner's diagnosis with their family. His difficulties in talking about the emotional impact of the situation are also visible when he distances himself from any formal support.</p> <ul style="list-style-type: none"> ✓ <i>Managing together due to less disruptive chemotherapy regime</i> ✓ <i>Distancing himself from formal support</i> ✓ <i>Needing time to be able to share the threat of losing partner with people</i>

Table 6.4.5 Continued Cross Case Longitudinal Theme 3: Trying to share the burden of caring

Cross Case Longitudinal Superordinate Theme 3: Trying to share the burden of caring	
<p>Time 2: Dealing with the impact of caring mostly on her own</p> <p>By the time of the second interview, Victoria does not seem to seek any formal support. This seems to be related to accepting the terminal diagnosis of her partner. As a result, her partner's GP becomes the main source of support. She continues struggling with sharing the burden of care with other people, especially in the context of her partner's physical decline.</p> <ul style="list-style-type: none"> ✓ <i>Accepting the situation leading to not seeking further support</i> ✓ <i>Appreciating support from the GP</i> ✓ <i>Negotiating the burden of the situation with people</i> 	<p>Time 2: Focusing on sharing the "good news"</p> <p>Similarly to the first interview, Alan continues to distance himself from any formal support. However, in the context of his wife's improving situation, he describes a positive impact of being able to share this news in the family.</p> <ul style="list-style-type: none"> ✓ <i>Not being part of the support sought by his partner</i> ✓ <i>Readily sharing "better news"</i>

Participants' experiences of seeking and utilising support differ. Louise and Michael both seek support from other people following the diagnosis and, to a certain extent, are able to receive it either from family or health care professionals. With time, they seem to need less support and are able to have their needs met. In contrast, Anthony and Victoria experience challenges in obtaining support, which in turn have a negative impact on them. While for Anthony this feeling and perhaps need for support seem to decrease with time, Victoria struggles with engagement with formal support and also does not feel supported by people on a day-to-day basis. In contrast to other participants, Alan does not seem to engage with the formal support system and seems to deal with the emotional impact of the diagnosis by himself.

At the time of the first interview, Louise describes a number of sources of support available to and utilised by her, which she mainly considers as beneficial. Louise highlights support from her employer in dealing with the challenges of caring for her partner and especially appreciates being able to request annual leave to support her partner when going through the treatment. The positive impact of that is visible as she repeatedly describes it as "fantastic":

And I've had no problem whatsoever with operations and having time off and no. So it hasn't, no work hasn't impacted on me at all because any time I've needed off, I haven't had to struggle to get it, you know, they've been fantastic with me, absolutely fantastic.

In the health care system, the Clinical Nurse Specialist (CNS) seems to play a key role in supporting Louise. She values the nurse's availability in responding to her concerns and the CNS seems to act as a co-ordinator of care for Louise's partner. This is particularly important, as she seems to assume responsibility for her partner's progress:

Myself, I can ring her up and talk to her [...]. If I feel anxious about anything, I can just pick that phone up and phone X [CNS] and she will call back, or I will speak to her straight away.

While Louise appreciates the support from the CNS in dealing with some of her concerns, she describes a lack of information regarding the future treatment plan for her partner. After her partner was discharged from

hospital, she feels that they are both lacking information. She does, however, acknowledge the complexity of her partner's case as contributing to the potential lack of information:

I think in between operations, I think we both felt that we were out of the loop somewhere or other what was going on, you know, we weren't getting enough information. But there's been so much going on inside him that how can anybody keep up anyway, you know. But I think, there was just the once that we just felt that nobody's talking to us, nobody's telling us what's actually going on, you know.

Louise also feels supported by her family and friends, which seems to lessen the emotional impact of the diagnosis. The feeling of having support comes from receiving regular phone calls as well as visits to enquire about her partner's well-being. This seems to be enough to lessen the burden of caring for her partner. This is similar to her partner's experience, who also describes the support from the family and the benefits of regular contact with them:

We have at least once or twice a day, someone is phoning us up to find out how X [patient] is, you know. [...]. It might just be a chat on the phone, or when he first came out of hospital, his sister and brother tried to get, because they don't live here, they live in X [city name] and but they tried to come down to actually visit, you know, to see us. Otherwise it's a call on the phone, but just to sit and chat on the phone is excellent.

While all the other sources of support seem to focus on meeting her partner's needs or her needs in relation to caring for her partner, support from friends seems to be unique in being able to meet her own emotional needs. She also appreciates support from friends, who seem to replace the need for formal support. When asked about her support needs, she replies:

I don't need therapy or anything like that. I've got really, really good friends, well they're both of our friends, but I mean I've got really good friends at work. All the support I need at work, all the support I need.

At the time of the second interview, Louise appreciates ongoing support from work, family and friends as well as health care professionals. It seems that the frequency of phone calls initiated by Louise herself might have also decreased, as she talks about them hypothetically, while initially she described them as happening in the present:

They've all been really good. We don't very often get calls to say, how are we doing, or anything like that. But if I wanted to phone X [CNS], who's X [patient] colorectal nurse, if she wasn't there, if I had to leave a voicemail, she would ring us back. So the support is there, yes.

She also appreciates the support received from the GP in managing her partner's difficulties with bowel movements. She recalls the situation when she was worried that they may not be able to access more expensive medication, but is reassured when it becomes possible. Similarly to the initial interview, Louise also values the ongoing support from friends and family. When asked how she copes with the situation on a day-to-day basis, she describes the availability of support from both within and outside of work. She seems to value sharing her worries as a way of managing the distress caused by the diagnosis:

I maybe talk to a friend that helps, by sharing. Well I'm at work most days and I've got a really good bunch of people that I work with. And I've got another good friend that doesn't work in my place, you know, so it's just nice to sit and to be able to talk to somebody, you know.

This support seems very valuable to her. Her partner also seems to see talking to people as an important aspect of his experience, but this is mainly in relation to raising awareness of his diagnosis and helping other cancer patients to deal with their experience. They both seem to gain strength by talking to people but this sharing serves a different purpose. She also seems to reflect on the overall support from the healthcare team. The uncertainty regarding her partner's treatment options, which she describes in the initial interview, has been resolved, and she feels this in turn seems to facilitate the feeling of being better supported by the clinical team:

So I think, I suppose at the beginning X [patient] felt a bit out of, on a limb, because he wasn't getting the support he wanted because he had so many different things wrong with him. [...] He did feel a bit out on a limb. But I think now, I think we've got the support we need.

Like Louise, Michael seems to also benefit from support, but in his case mainly from health care professionals rather than family. Following the diagnosis, Michael describes the support received from health care professionals in caring for his partner. As family members are not available to support him, Michael has had to face the time since diagnosis on his own. This lack of support is not only evident in facing the critical moments such his partner undergoing an operation, but also in dealing with the day-to-day impact of the diagnosis. Although Michael acknowledges support from his family, as they live at a distance they are not able to provide the much-needed face-to-face support. While Louise seems to find the telephone support beneficial, this does not seem to be enough for Michael:

Support from family, virtually non-existent to be honest, apart from, like I say with my lot are 150 mile away, but yes, they would telephone, yes they would text, yeah, they would, that sort of thing, that sort of support, but actually physical support, there was just the two of us.

The need to share the burden of being a partner to a person with cancer recurrence is visible here. The lack of support from the immediate family leads to locating trust in the CNS. We can see the elaborate way of protecting his wife from knowing about the need for support by trying to fit the phone call around the time when she is not available. The reason for seeking support is not necessarily because of the inability to talk with his partner, but rather from not wanting to burden her with his emotional needs. The conversations with the CNS seem to be rare occasions when Michael is able to talk about his needs and the impact of his wife's diagnosis on his life:

Unbeknown to X [patient] I ring her specialist nurse every now and again, to speak to her, because other than X [patient] really, I haven't got anybody if I want to speak to, and sometimes I find it difficult, and it's, I speak to X [CNS].

Michael's wife, Kate, also locates her trust in the CNS and health care professionals, in the absence of the support from the family. The support is not only based on gaining reassurance and practical support but also having someone to talk about his experience. Both Michael and Kate seem to use the CNS in this way, which allows them to protect each other from talking about the distressing nature of this experience.

Similarly to Louise, seeking practical support including advice regarding his partner's symptoms is also important to Michael. It might be that the threat of another recurrence, indicated by possible symptoms, cannot be verbalised with his partner and can only be shared with the CNS. He seems to monitor his partner's symptoms, which cause concern, and consequently this needs to be shared:

If I want to speak to somebody that I've got her, because there are occasions that you, you do need to speak to somebody. She's going through this thing now, she's had this fantastic weight loss, you know, she's lost three and a half stone, she's constantly got nausea, she's constantly feeling sick, and it is worrying, and she, I speak to X [CNS], and X [CNS], she, you know, she puts your mind at rest.

Regardless of the support received from nurses, Michael also recalls some challenges in caring for his partner following the operation. While for Louise these were mainly related to the lack of communication between her, her partner and the clinical team, for Michael they are related to providing personal care for his partner. We can see how becoming a carer to his partner is negotiated by both him and his partner. While personal care activities, perceived as intimate, seem to be difficult for his partner to accept, Michael seems to accept them and in fact he is willing to take on a carer role. This seems to be facilitated by his professional background as a nurse. However, the bond with his partner also seems to be a significant factor and Michael perceives caring in this way as part of their relationship:

R: At one stage she couldn't fasten her bra, she couldn't do things, I was having to do things like that, I had to help her dress, after the liver surgery she couldn't, she couldn't do it, I think she found that a bit, perhaps not, embarrassing's not the right word, but she didn't think that I should be doing, should have to do something like that,

not that we, I don't mind doing it, it's the fact that, it's the principle of the thing, you shouldn't actually be doing it [...].

I: What did you think?

R: I didn't mind, you know, I was trained as a psychiatric nurse, I nursed for 10 years, psycho-geriatrics, I've had my hands in places that I never ever thought, it doesn't bother me, doesn't bother me one bit, if I can't do it for her, who can I do it for.

At the time of the second interview, Michael appreciates ongoing support from the CNS, which still seems to compensate for the lack of support from their family. However, it seems that the nature of support also seems to evolve. As initially, "when his partner was ill", it was mainly to cope with her physical suffering in the period of recovery following the operation and the impact of this on Michael, the CNS also now provides now support in dealing with his partner's diminished well-being:

I spoke to her, because X [patient] was, it was that time she was extremely, extremely low, she was crying, but she wouldn't tell me what she was crying about. She has a lot of pain some days from the bowel area, but it's more psychological with her.

In contrast, Kate, his partner, does not seem to seek emotional support from the CNS any more. It might be that as she is an active member of the support groups and cancer network, she gains her support from them.

Michaels also seems to appreciate the availability of the GP when concerned about his partner's symptoms. He seems to take on the role of the carer as it is he who initiates contact with the doctor. Similarly to Louise, he appreciates having priority access to the GP as it seems to ease the responsibility and he is able to hand over the caring to the professionals.

While both Michael and his partner seem to appreciate and benefit from the support received, with time they also seem to identify the limitations of it. Here, Michael seems to undermine the value of the support from the nurses as they have not been through the physical experience of treatment themselves. This, in Michael's opinion, gives his partner more credibility in giving advice to other patients, as she is able to draw on her experiences. In fact, Michael seems to present the unique experience of his partner's cancer to a certain extent as a rule. Her experience seems to be presented

as potentially everyone's experience as well, where symptoms experienced by his partner are likely to happen to others as well. Interestingly, Michael also perceives the psychological support as particularly related to the role of the CNS. This may be connected to the fact that he received much valued emotional support from the CNS:

As far as we're aware, that all the specialist nurses, not one of them have actually gone through cancer, and they are trying to say to you, who's got cancer, you should be doing this, that and the other sort of thing, but they have never gone through the pain, and whatever you want to call it, of having chemotherapy and radiotherapy, they've never done it. [...] The professionals can support them, obviously within things that we can't support them with, with like the psychological side of it, but from a practical side I think that [patient] can help more, you know, because is this going to happen, is that going to happen, you say yes it is or no it isn't, it didn't happen to me, or it did happen to me or something.

In contrast to Louise and Michael, Anthony and Victoria experience difficulties in obtaining support. At the time of the first interview, Anthony describes a number of health care professionals, family members and friends whom he comes into contact with following the news of the recurrence. Throughout the interview, we can see the impact of these interactions on Anthony. The context of his wife's initial diagnosis was challenging for him as his wife had to undergo an additional operation following a mistake by the surgeon. When it comes to the news of recurrence, he is also faced with what he perceives as a lack of compassion and care from another surgeon. The clinician tells Anthony that he is not able to help his partner within minutes of looking at the scan, which Anthony perceives as arrogant and insensitive. As the diagnosis of recurrence was received only 5 months following the initial surgery, current disappointment and frustration with the system is magnified by previous negative experiences. During his first interview, he talks at length about these experiences.

Following the surgery, his disappointment with the system seems to continue. He is overwhelmed with caring for his partner at home and wants health care professionals to share with him the burden of providing support. While Michael was initially able to gain both emotional as well as practical

support from the CNS, Anthony seems to struggle. Here, Anthony describes his feeling of hopelessness when managing his partner's pain. The loneliness of the experience is visible when he is left to try to find solutions on his own. The support from health care professionals in Anthony's opinion has two aims, also implicitly described by Michael: to ease the suffering of the patient and to provide reassurance for the partner. Interestingly, we can see how in this context, Anthony identifies himself as a carer rather than just a "partner", which highlights that in fact he may see himself as the main provider of care for his partner. He realises that his lack of knowledge and experience with pain may mean putting pressure on services, but this in turn further contributes to his distress:

I'm talking, possibly talking through my hat here, but somebody like a Macmillan nurse or a district nurse who's fully au fait with medication, can say yes you could do with something else here, that could help. It would ease the patient's problems and also the carer's, they know that there's someone there looking after the loved one, [...] because you're knocking your head against the wall, what can I do to resolve the problem, wasting people's time and money, the doctor coming out when it's not always necessary.

Anthony partially attributes his difficulties in establishing his role as a carer to the fact his partner does not ask for help. While he accepts that he needs to give his partner some control, he feels this needs to be balanced with the provision of appropriate support. While he is required to provide care for her on a day-to-day basis, he is not able to be involved in the decision making related to her care needs. Here, he highlights the importance of a carer's involvement in the management of patients' difficulties:

She says I do not need anything [...]. I also accept that although I'm her husband, I can't make decisions for her, appertaining to herself, where professional doctors, nurses etcetera, they ask the patient, and that's the end of it. If the patient says one thing, doesn't matter what the spouse, husband is saying, they can't, they can guide but they can't do anything else apart from take instruction from the patient.

Linda, Anthony's partner, does not seem to mention this perceived lack of support in her interview, which may highlight, as her partner suggested,

that this is not an issue for her. This discrepancy magnifies the challenge of caring for Anthony.

In contrast to his experience with other health professionals, similarly to Michael and Louise, Anthony seems to appreciate support from the GP who, in his opinion, demonstrates flexible support by being available both face-to-face and on the phone.

Anthony also describes the difficulties of sharing his day-to-day caring with people other than health care professionals. Unlike Louise, he does not perceive numerous phone calls as an opportunity to share his concerns but rather as a painful reminder of the severity of the situation. He seems to relive the suffering every time he is asked about his partner's well-being. He also seems to distinguish between genuine and non-genuine support. Phone calls seem to represent the latter as they do not replace face-to-face contact, which could lessen the burden of caring for Anthony. What is also striking is that no one seems to ask about Anthony's well-being and needs, not only in relation to caring for his partner but also his day-to-day life. As was the case for Michael, he feels deeply the lack of a physical presence and lack of interest in his needs:

After two or three phone calls by the same person, week in, well, two or three times a week, if they haven't come within a month, why don't, why don't you stop phoning if you're not that far away. If you're so interested, come and knock the door, pop round the corner and see her, if not, please stop because I found it very hurtful to have to keep explaining that X [patient] is not well and she's in pain. There's nothing I can do about it, it gives me pain to keep telling you that she's in pain.

In contrast, Linda also describes the support from family and friends but she perceives it as sufficient and is appreciative of it. It might be that she has different expectations towards how the support should be offered at this time. It is also possible that she has different needs to Anthony.

By the time of the second interview, Antony's partner has regained physical strength and had a clear scan. This is described by Anthony as "a second chance" and seems to dominate Anthony's account, in relation both to how he perceives the support now and in retrospect. The "second chance"

seems to represent not only a hope for cure, but also a restored faith in medical staff, who in Anthony's opinion did not give up on his wife by operating on her. Positive feelings of appreciation seem to relate to support received from the health care system, as well as from family and friends. The loss of trust in the system, clearly visible during the first interview, is slowly regained here, mainly because of the positive experience with another clinician. A number of factors seem to contribute to this feeling. Firstly, Anthony appreciates the fact that the clinician keeps his promises and also treats Anthony and his partners as unique individuals. Secondly, compassionate care does not only mean being cared for, but also efficient care. He comments on the clinician's efficiency in ordering tests and ensuring that they are done. Anthony also comments on the value of being treated as an equal by the clinician:

You feel you're the only patient he's got. He makes you feel that important. You feel privileged to be his patient, they feel the same way. He's such a laid back guy, I presume he's in his thirties or early forties, laid back, and he puts everything he's thinking into layman's language, even draw you pictures if you like, this is what we're looking at, this is what we want to do.

By the time of the second interview, we can see also the change in how the previously received care is perceived. The previously perceived lack of care and compassion seems to be now seen as merely "hiccups". It may be that in fact, his partner's regaining of physical strength means a lesser need for support and in turn, less pressure on Anthony. However, we can see that he also seems to reflect on his previous feelings and the potential impact of his feelings on the perception of care:

In general I have been happy with the nursing that came here. Obviously there's always hiccups and as a husband and as a patient, you, at the time don't always think there is some other people about, which there are, that require nursing, but they were very good, they turned up, and both our local GP and the nursing have been excellent and I could not ask for the better care. There were occasions when you just feel as a husband, just sometimes one felt absolutely useless and that could be turned into frustration, anger.

While Linda also describes the change to her situation, she continues being very positive about the support she has received from the family and friends. In contrast, we can see the reason for change in how the support is now perceived by Anthony: Linda's improvement has an impact on his feelings towards the support. The change of feelings and, in turn, how the situation is seen by Anthony seems to be summarised in his final statement:

Just pleased to be where we are today.

However, similarly to the experience with the clinical team, the feeling of disappointment with care did not seem to go away completely as he continues to reflect on the experience with Macmillan nurses. As this support seems to refer to a more overall assessment, it may be still perceived by Anthony as relevant and as such upsetting. Specifically, he perceives the face-to-face assessment and contact as lacking. Again, the feeling of being treated as a number is particularly upsetting for Anthony:

I would say the only people who didn't turn up were the Macmillan nurses [...]. I presume there was memo on the memo pad, some memo somewhere, there's a number of people who need to be contacted or should have been seen, I'll give a quick phone call. I didn't see the point. [...] It felt quite obvious to me it was just a tick box mentality.

The reason for the perceived disappointment with community services might be also related to Anthony's expectations. It seems that the operation and another appointment to confirm the clear scan seem to signify the end of the intense support needed from the secondary care services. Although Anthony and his partner are still waiting for the appointment regarding the time of stoma reversal, he seems to see the clinician "moving on" as a natural transition. He also seems to believe that caring invested in supporting his partner fuels that need.

He [surgeon] moves on, we move on, because it was such a traumatic experience I think not only for him and his team, it certainly was a traumatic experience for X [patient], to have such a long operation. I think it was just shy of a few minutes off seven hours.

It may be that he sees that he is now transferred to the primary care services and hence the lack of support from community services is perceived as an indication of poor care. Similarly to the perception about support from the clinical team, Anthony seems to present a more positive description of the support received from other people at time of the second interview. He reflects on the support he and his partner received following the operation. Interestingly, he also recalls people visiting, the lack of which he previously found very distressing:

But numerous people came and sat with her, brought books, read to her, all sorts of things, and they were very supportive, other friends, that she wasn't prepared to eat, people came, cooked meals, flowers, chocolates, it was an ongoing thing that people were here.

While with time Anthony seems to regain some hope and trust in support from both health care professionals and family and friends, Victoria seems to leave the support of health care system behind and struggles with sharing caring for her partner with others. At the time of the first interview, we can see a slowly diminishing hope for support from the health care system as time progresses. Victoria's partner has been living with a recurrence for the longest period of time when compared to other patients and as a result, her first interview covers her experience of seeking formal support for both first and second recurrence. Throughout the first interview, Victoria describes her disappointment and surprise with the lack of support for patients with cancer, and colorectal cancer in particular. She seems to contrast the perceived availability of support for breast cancer patients with colorectal cancer and relates the less visible presence of colorectal cancer in the media in general to the fewer support services available.

There seems to be a lot more, I don't know, in the news, and there seems to be a lot more publicity and support for breast cancer than there does for other types, like it's almost a bit more trendy or in the media, whereas bowel cancer is not really talked about and it's a bit more, I don't know, off the radar, even though it's just kills just as many people as breast cancer, or even more. Yeah, it's sort of, we have been quite, both of us have been quite surprised at the lack of things out there.

Following the first diagnosis of recurrence, Victoria starts to go to counselling, which she initially values. The ability to share her feelings without limits seems to be particularly appreciated. This ability is in contrast to the barriers she perceives regarding sharing feelings in the family. She seems to acknowledge the need to protect each other as one of the reasons behind the inability to express her feelings. However, Victoria also describes the limitations of the support offered as it seems that it is not really tailored to the fluctuating nature of the illness. It does not seem to meet her more ad hoc needs, such as the times when she feels overwhelmed with the burden of caring for her partner. Equally, it is also difficult to commit to a regular appointment as the unexpected “good day” can provide a much needed respite, which she does not want to spend talking about the situation. These difficulties make her question whether she in fact should commit the time to meet her own emotional needs. She also seems to realise the difficulty of finding this balance herself, as she concludes:

I don't know how I'm going to be in two weeks, it might be a day where or a week when X [patient] is having a good week and we want to do things, we want to go out with the kids or do whatever, we don't want to sit talking about the situation and getting upset about it al. So it's sort of a fine line between wanting to speak to somebody and not wanting to keep going over and over and over it again.

James, Victoria's partner, also highlights the benefits of talking about the situation and in his first interview he describes his unsuccessful attempts to encourage Victoria to talk about her feelings to him. It might be that due to the distressing nature of her experience, she is not able to share them with him. Following the diagnosis of recurrence in her partner, Victoria gave up work. As a result, she gained a valuable network of support from other mothers, with whom she was able to share the diagnosis, and who are sometimes able to lessen the day-to-day burden of caring. While Victoria feels supported by people who share her day-to-day challenges, she describes limitations to the understanding of her situation from people who are not necessarily part of her day-to-day life. While Victoria and her partner want to maintain some social life, this comes with certain challenges. While Anthony describes initially the feeling of other people not

appreciating the challenges of caring for his partner, for Victoria this feeling is related mainly to intermittent visits from friends. As visits are only scheduled when her partner is feeling well, friends have only partial access to her experience as a carer. In fact, not seeing the partner on a bad day means that they are not really aware of the severity of the situation and the impact it has on both of them. We can see how she feels that people may undermine the severity of the situation, in the context of lack of visible and present symptoms on a “good day”. We can see the impact it has on Victoria, as she lists what is happening on a typical “bad day”:

And you know, a lot of friends have been to see me and things, but it is, it is a bit difficult, because they don't really understand what goes on, you know. I guess the only time we schedule people to come and see us, either my friends or X's [patient's] friends is when he's feeling well, and everybody kind of goes oh, don't you look well, oh, like they wouldn't believe that anything was wrong with him, but they don't see him on the days where he's in bed and he's feeling sick, and he's just had his chemo and he's so tired he can barely get up. They don't see all of that, so it's kind of hard for them to really understand how it is.

The feeling of lack of support from the system seems to be consolidated at the time of the second interview for Victoria. She describes numerous attempts in trying to access services for both herself and her partner and the difficulties in obtaining that support. Similarly to the initial interview, Victoria does not seem to seek any further support. As the certainty of the situation increases and the hope for cure seems to decrease, so does the need for support:

Well, I guess when I first went to see the counsellors it was, X [patient] was still having operations, he was having chemo, and we thought he might get better, but now we know he's not going to get better, and we've had to sort of come to terms with that ourselves really, so it's kind of, you know, make the best of it really. You know, it's been, it's been difficult to sort of accept it, but I think both of us are sort of accepting it.

However, like the majority of partners, Victoria seems to appreciate help from the GP, who provides varied support. Although, we can see the

limitations of the support, as the only person available to “talk to”, this support is especially valued by Victoria.

Similarly to her initial interview, Victoria describes the lack of understanding of people who do not share day-to-day life with her. There does not seem to be any change in how she perceives this. However, this feeling seems now to extend to the family as well. While Victoria seems to appreciate the support received from the family, she also feels that they do not understand the impact this situation has on her. She seems to be more accepting of the lack of understanding from her friends than from her family. It may be that since they can see her partners’ suffering on a day-to-day basis, they should also understand the impact it has on her. Here she describe a recent situation when she was ill herself and the multi-layered impact of that on the family. Passing responsibility to her partner generates an unwelcome reaction in the family. We can see Victoria’s’ frustration and feelings of the unfairness of the situation. This rare instance of her not being able to be in charge of all the chores brings to the forefront the fragility of the current situation to her:

On the Wednesday I was ill, I had like a vomiting bug, so I was completely out of action and he [patient] had to take the children to school on his own, and then his mum was going mad because he had taken the children to school on his own and he should have got somebody else to do it, and it’s just, you know like you’re not allowed to be ill, I’m not allowed to be ill because I’ve got all these other things to do.

While James does not comment on this particular situation, he talks at length about the burden of his illness on his partner’s life and his attempts in trying to lessen the burden after his death. He might be aware of the limited ways in which he can help his wife at present and hence his efforts are mainly focused on the future.

While Louise, Michael, Anthony and Victoria seemed to seek support, Alan’s experience seems to be a more lonely one. While he seeks some support with the practical aspects of caring, the emotional impact of the news, clearly distressing for him, he seems to process on his own. He seems to be focused on his wife’s needs and puts his needs in the background. By the time of the first interview, Alan and his partner have

sought support from the partner's sister to ease the burden of day-to-day caring. The decision seems to be motivated by the previous experiences of treatment as physically demanding. The chemotherapy following recurrence seems to be less challenging than expected and when this is realised, Alan and his partner are able to cope on their own. It is his partner who seems to take the initiative to manage on their own, although Alan seems to agree with the decision as well. Support from the district nurse along with support from his partner's sister seems to be enough to manage on day-to-day basis.

She [sister] stepped into the fore yet again, this January, when the chemotherapy would be started. This time the chemotherapy was not as, what's the word, not as difficult, shall we say, as the first time. It seemed slightly easier; it didn't seem to affect so much. So anyway, she's actually gone back down now to X [city name] and we're sort of, you know, cope on our own. And her sister monitors all the medication and things like that. [...] We have a district nurse comes in to do the sort of secondary aspects of the sort of health as well.

Alan also does not seem to seek support from the health care professionals for himself. He describes a number of sources of support which his partner uses and seems to benefit from on both emotional and practical level. Alan seems to highlight "sharing the experience of cancer" as bringing his partner and other people together. It may be that not sharing these experiences is the reason for not seeking similar support for himself or that he does not feel he could demand support, given that it is not him who is ill:

She has a lot of support, in the sense that she has, she's been going to a therapist and she has these support sort of groups. [...] No, there's no support for me. I don't need any support; I don't need it because, as I say, I can cope alright.

While he describes that he does not have any support needs, we can see the emotional impact of the situation on him when he describes the challenges of sharing the news with the family. The distress caused by the diagnosis is overwhelming and difficult to share with people. It seems that only after he processes the news himself and is able to face the meaning of

it can he share this with people. Similarly to Anthony, sharing the news and talking about the severity of the situation seems to cause severe distress, and seems to be an ongoing reminder of the situation:

And I couldn't talk about it for two months. But as you go over it in your mind, you rehearse the story to tell people and in the end, you know, you sort of almost accept it really.

As he continues, we can see how he negotiates the disclosure of news and ongoing information regarding his partner's health. His emotional state seems to dictate how much is shared with others in terms of the overall prognosis. However, similarly to Anthony, being able to discuss the situation is in fact initially too challenging for Alan as seems to be a reminder of the reality:

But with all members of, like you have to sort of, people are asking all the time and you have to sort of say, depending on your mood, how much you could sort of say. And you just sort of say, oh she's not too bad but it is serious, you've got to convey some impression that, you know, this isn't to be treated lightly, it's a serious situation. But to talk to people in detail is difficult for some weeks, until you sort of adjust your head to the situation, the reality, and that's the situation I was in for a while. But, as I say, I'm able to talk about it now.

While Alan seems to indicate that he is able to talk about it in the family, it may not apply to his relationship with his wife. In her interview, Johanna describes her struggles in being able to talk to her partner and sons about her poor prognosis. As a result, she utilises support groups as a platform for sharing her feelings.

By the time of the second interview, his partner's situation seems to be more stable. As she is not suffering from major side effects, there is no need for practical support from the family. In fact, throughout the interview, Alan focuses on his partner's ability to continue with her pre-diagnosis activities. Similarly to the initial interview, he describes the extent of the support received by his partner from online as well as face to face support groups. He does not seem to have any contact with health care professionals and distances himself from seeking any support. Again,

sharing the experience of cancer is what brings his partner and other people together and it seems that as a result Alan does not see his place at these meetings:

And she meets other people who are in a similar situation and she's been going there for six months, one day a week, which she's loved, absolutely loved it. [...] And talking to people in similar situations, which she's found, which she always has found helpful. She's with, she's on the internet all the time.

As he continues to describe, he seems to find fulfilment in work. The difficulty in sharing his feelings and the emotional impact of the diagnosis may suggest that Alan does not want to seek support as this would mean discussing feelings which he may find too painful at this stage. As his partner is receiving support, which she benefits from, he does not see his role in that. This in turn allows time to focus on work:

I don't, no. I don't, I just have my own sort of life. She gets support, as I say. My life is all about, it's just about working really, working. So that's where we are.

Following the news about chemotherapy being effective in receding cancer, Alan describes the positive impact that sharing the news had in the family. Not surprisingly, sharing more positive news is done much more easily than the initial news. Throughout the interview, he refers to the positive impact the news had on everyone. This is in contrast to how slowly and carefully the initial news was shared. This may highlight the difficulties for Alan in sharing the potential emotional impact of the situation with others. Similarly to Anthony, throughout the second interview, Alan focuses almost entirely on the "positive news" from two scans and the impact of that on both him and the family:

Anyway, about June time she had the second scan, and again that was a very positive one, which lifted her morale and everybody's morale having had two.

This is contrast to Johanna's interview, when she describes her need to talk to someone about her funeral and final wishes. She seems to be aware that her partner would struggle to fulfil this need and as a result, thinks about

other people who could help her in this. This in turn, seems to create emotional distance between her and her partner.

6.4.6 Part B-Discussion of the Cross Case Superordinate Longitudinal Theme 3: “*Trying to share the burden of caring*”

The third Cross Case Longitudinal Superordinate Theme “*Trying to share the burden of caring*” explores partners’ attempts at trying to share the news of the diagnosis of recurrence, as well as the burden of caring, with health care professionals and family and friends. Interactions and relationships with people from both within and outside the health care system seem to be very important to partners and can have a big influence on how they experience their caring role. Firstly, I will focus on partners’ experiences of interactions with health professionals and discuss the importance of support from the health care system. Secondly, I will present the relationships with family and friends in the wider social context, including sharing the news of recurrence with other people as well as seeking and receiving practical support.

Supporting partners is crucial as they often provide ongoing care to patients at home. The current study demonstrated that partners needed support in a number of areas following patients’ diagnosis, including pain management, dealing with bowel problems or managing side effects of treatment. They often felt that they lacked knowledge and experience in being able to help patients, which contributed to their distress. One of the important needs was also being able to make sense of new symptoms, which could mean disease progression. Partners seemed to monitor patients’ physical well-being on a daily basis, with new as well as persisting symptoms bringing worry. However, it seems that with time, especially partners of the patients who were recovering well from the surgery, felt more confident in providing care and dealing with arising problems. It might be attributed to a decreasing need for support because of fewer symptoms, or an increasing confidence. Equally, those partners of patients with a poorer prognosis had to adjust to the changing side effects of the treatment, which was difficult. In that context, partners found support from health care professionals crucial. They described the value of the GP in coordinating care, arranging psychological support and referring patients for further tests. Partners also placed great importance on being able to access help to be able to deal with symptoms. While the GP was often the first point of call, they also felt

that they could not always provide specialist support. In the light of that, they valued support from the CNS who could provide information and reassurance about the meaning of symptoms or arrange further investigations if needed. In contrast, the lack of support in dealing with symptoms, especially pain, made some partners feel hopeless and seemed to contribute to the perception of care as of poor quality. To date, the practical needs of carers after discharge home were mainly highlighted in the context of palliative care, when carers are recognised as providing “hands on” support (Soothill et al., 2001). A recent systematic review on the needs of informal carers providing home-based end of life care highlighted a number of tasks in which carers are involved, including managing medication, monitoring physical symptoms, overseeing nutrition and providing personal care (Bee et al., 2009). The role of health care professionals, especially primary care, was recognised previously as a significant factor for patients in palliative stages in providing support for family members, including arranging regular visits, coordinating care and providing emotional support (Payne et al., 1999). Studies exploring the experiences of partners following patients’ initial treatment also highlighted the need to provide support for partners in dealing with the meaning of symptoms. However, the needs of partners at the time of recurrence may be more complex given the uncertainty of the future and the possibility of future progression. Thus, both monitoring symptoms as well as providing “hands on” care might be important for partners to feel confident in being able to deal with.

Some partners also sought emotional support which included support from psychologists and the CNSs. Partners sought psychological support for a number of reasons, including dealing with the uncertainty of the situation or being able to talk to someone. Seeking psychological support did not necessarily mean that they were not able to talk about their feelings with patients, but were motivated by not wanting to talk about their feelings only to patients. For some, emotional support came mainly from the CNS, where practical and emotional support seems to blur in the instances of seeking reassurance about the worrying symptoms. The need for emotional support seemed to be the most significant at important transition times and times of uncertainty. It is also important to highlight that those who did seek psychological support often found it inadequate. Partners identified barriers

to accessing and using support including difficulties in attending regular sessions in the context of unpredictable illness, lack of support specific to younger partners or perceived lack of compassion. Previous studies have also indicated that availability and uptake of psycho-social support varies among carers (Soothill et al., 2001). While previous studies looking at partners at the time of recurrence lack any information about their psycho-social needs and access to formal support, the current study highlights that partners do want someone to discuss their concerns with.

Sharing the news of a patient's diagnosis with other people seems to be an area of significant difficulty for partners. In the present study, this difficulty seems to be extended to family as well as a wider social context. While some felt supported, others found that having to tell other people about the diagnosis and continuously inform them about the patients' progress was particularly distressing as it was a reminder of the severity of the situation. Others found that they lacked any interest from families or commented on a lack of opportunity to discuss their own feelings with people. Previous studies of partners with cancer recurrence focused mainly on the difficulties of discussing the diagnosis between the patient and their partner and found that spouses were more willing to discuss their treatment-related concerns with patients but less willing to discuss their feelings and concerns about mortality (Chekryn, 1984, Lewis and Deal, 1995). The current study highlights that disclosing the diagnosis and negotiating information and the emotional impact of the illness also happens in wider families and not only between the patient and their partner, and can have a significant impact on the partner.

The importance of practical support from families and friends has also been previously recognised. The extent of the practical support from people other than health care professionals seemed to vary in this study. For some partners, the feeling of loneliness did not only extend to the difficulties in talking about the illness with others, as described earlier, but also an understanding by other people of what the illness meant for partners on a day-to-day basis. Wider families and friends did not necessarily always appreciate the difficulty of caring for patients. Visits from friends who saw patients when they were relatively well did not provide a full picture of partners' responsibilities, which may have resulted in less or no support being offered. As a result, partners described feelings of disconnection from

others, often due to physical distance between them and family members or friends. In the instances where other people were not able to be part of their lives on a daily basis, they particularly struggled to feel understood by other people, which created emotional distance. However, even when family members were present in their lives, partners often felt that they wanted them to focus entirely on the patient's needs and did not seem to appreciate the demands of providing care. On the other hand, some were able to access some support from friends or family in the period around the time of treatment, which was valued. However, it tended to focus on meeting needs of patients rather than partners. It might be that family and friends perceived the patient as being the main person affected as her or she was suffering physically. In this context, physical suffering was a more visible aspect of the impact of illness and as result, was able to trigger support. Caring for the patient seemed to happen in the background and as such was not recognised by others as a burden. For most, it meant that partners were often virtually the sole carers and often described their feelings of abandonment. This feeling seemed to diminish to some extent when better news was received, which may suggest that the burden of caregiving may be magnified by the loss of hope. The importance of support to partners was highlighted in previous studies: partners who felt supported at the time of recurrence reported fewer difficulties in carrying out their caring role and reported lower levels of hopelessness (Northouse et al., 1995). However, the current study demonstrates why some people may not feel supported and how people perceived whether their support needs have or have not been met.

Chapter 7: Discussion

7.1 Overview

Recurrence of colorectal cancer is a major event for patients and partners. The meta-ethnography on the experiences of patients with cancer recurrence (Chapter 2), and the literature review on issues faced by partners (Chapter 3) highlighted a variety of difficulties that both patients and partners face when cancer recurs. These reviews also demonstrated a paucity of studies exploring the experiences of patients with colorectal cancer and of partners of patients with colorectal cancer at the time of recurrence. The research reported in this thesis has tried to remedy this deficit. Chapter 4 describes the Interpretive Phenomenological Analysis (IPA) methodology used in the current study, which was chosen for its focus on the individuals' experience. Chapters 5 and 6 present the analysis of the longitudinal interviews with patients and with partners respectively and discuss them in the context of the current empirical evidence. This chapter discusses key findings in relation to each Cross Case Longitudinal Theme for patients and partners and how each theme contributes to current theoretical debates. It also considers the implications for clinical practice and makes recommendations for further research. Finally, it provides my reflections on my experience of conducting this study and considers its strengths and limitations.

7.2 Key findings in relation to Theme 1 for Patients: “*Making sense of the meaning of the diagnosis*” and Theme 1 for partners “*Making sense of an unpredictable illness*”

Theme 1 for both patients and partners described the process of making sense of the diagnosis and the challenges associated with this. Interviews indicated that the initial diagnosis is a significant reference point, when making sense of the recurrence. Similar factors seemed to have an impact on how the diagnosis of recurrence was perceived by both patients and partners. On the one hand, factors such as seeing the initial treatment as successful, perceiving the possibility of the cancer coming back as low and the patient returning back to work were reassuring, and thus contributed to a feeling of surprise and distress when recurrence was diagnosed. On the other hand, experiencing symptoms and focusing on the possibility of cancer coming back seemed to slightly lessen the initial feeling of surprise when the news of recurrence was given. These previous experiences

seemed to also have an impact on how treatment options and aims of further scans were perceived by both patients and partners.

This finding raises the question whether or not a diagnosis of recurrence is more distressing for patients and partners than the initial diagnosis. Previous studies have considered this question, but these have mainly been quantitative studies comparing levels of distress at the two time points, and very few of these explored their findings in the context of the current conceptual frameworks or theories. One of the exceptions is work by Andersen and colleagues (2005) who used two conceptual frameworks to consider whether cancer recurrence and initial diagnosis are similar or different. The first framework they considered is based on the principles of learning with habituation being a key concept. Habituation occurs when the reaction, which the stimulus initially generated, lessens with time (Domjan, 2014). Andersen and colleagues (2005) suggest that as a result of habituation, cancer recurrence should generate less distress as a number of areas will be familiar to patients, thus lessening its impact. They suggest a number of areas of familiarity. Firstly, treatments and their consequences such as disruption to day to day life; secondly, understanding of the health care system including established relationships with the clinical team; finally, being aware of resources to deal with consequences of illness including practical and financial arrangements (Andersen et al., 2005).

The second framework that Anderson and colleagues considered is based on the early work by Weisman and Worden who described recurrences as “secondary existential plight” (1986). This phase is similar to the initial diagnosis (existential plight phase) as the patient is trying to make sense of the meaning of the diagnosis and the impact of it on their life. However, according to Weisman and Worden, the recurrence stage also brings additional challenges of being confronted with the failure of the initial treatment, and consequently less optimism and reassurance about the future (Weisman and Worden, 1986). While the first framework, favoured by Andersen et al. (2005), focuses mainly on the similarities between the initial diagnosis and the recurrence stage, the second framework highlights how in fact there might be a lack of familiarity when patients are faced with recurrence.

While Andersen et al. (2005) and Weisman and Worden (1986) highlighted the important question of whether initial diagnosis and recurrence are similar or different, these two frameworks provided a rather limited insight into what the process of making sense of the recurrence may look like. It may be useful to consider Leventhal's Self-Regulation Model of Illness which aimed to explain difference in people's responses to illness. The model suggests that a person faced with a health threat constructs its emotional and cognitive representation based on three sources of information: the previously assimilated lay understanding of illness; external sources such as friends and family or health care professionals; and the current experience of illness encompassing symptoms and physical sensations (Leventhal et al., 1984). Emotional and cognitive processes influence each other: physical sensations can trigger thoughts about illness, which in turn affects a person's emotional status. According to Leventhal et al. (1992), there are five attributes of illness representations. These are: identity (the disease label often influenced by the image of the disease in the society); time-line (whether illness is considered acute/chronic or cyclical); the consequences of the illness including physical, social and economic ones; antecedent causes (e.g. behavioural, genetic); and finally, potential for cure and control. These attributes affect the emotional reactions to diagnosis and treatment (Leventhal et al., 1980).

The current study shows that patients do engage in an extensive process of comparing initial experiences and the experience of cancer recurrence to make sense of the situation. Being offered the same type of treatment (surgery) at the time of the initial diagnosis and recurrence was an example of facing to a certain extent a familiar situation, which in turn slightly lessened the distress. It highlights that familiarity may be helpful in managing the impact of recurrence. The comparison also seemed to take into account expectations towards treatment burden and recovery. Being surprised by lack of side effects of treatment, as they were experienced initially, or expecting to regain physical strength based on the previous encouraging experiences were examples of this process. For partners particularly, the comparison between initial diagnosis and recurrence in terms of treatment burden was important and could lessen or magnify their emotional distress. For example, less physically demanding surgery for recurrence in the liver in comparison with the initial surgery could in fact

lead to a perception that recurrence was in fact less serious than the initial diagnosis.

It seems that patients used previously assimilated information and experience to make sense of the current situation. Participants' illness representations which were created at the time of the initial diagnosis were questioned when diagnosed with recurrence. For example, the attributes of potential for cure and control and time-line were challenged when participants who believed to be cured and who perceived cancer as an acute illness were faced with cancer recurrence. Illness representations related to cancer being an acute rather than cyclical illness were especially challenged for patients who were offered only chemotherapy at the time of recurrence. This in turn could have explained their distress when hearing the news of recurrence. The illness representations were not fixed once patients were diagnosed with recurrence. Patients also compared their current physical sensations with previous physical sensations and as a result their illness representations changed. Similarly, partners compared their perception of physical suffering of the patient at the time of the initial diagnosis and at the time of recurrence. Subsequently, their illness representation could also be challenged as it did not correspond with their previous experiences.

While previous studies have highlighted the importance of Leventhal's Self-Regulation Model of Illness in the context of cancer, these studies focused on cancer survivors (e.g. Llewellyn et al., 2007, Traeger et al., 2009) rather than people with cancer recurrence. It is important to highlight that for patients and partners facing cancer recurrence, previously assimilated "lay" understanding of illness is, unlike for patients facing the initial diagnosis, based on their previous experiences of cancer.

It is also important to highlight that in contrast to Anderson et al.'s (2005) suggestion, familiarity with one aspect of the experience does not always seem to be a sufficiently protective factor in relation to the emotional impact of recurrence. For example, knowing the health care system may not be enough to balance the distress caused by not being offered the desired treatment. The model also assumes that by the end of initial treatment, patients have secured the required emotional as well as practical resources, which can then be utilised at the time of recurrence. Again, this

may not be the case and may in fact magnify patients' distress at the time of recurrence. Finally, while Andersen et al. (2005), Weismann and Worden (1986) and subsequently a number of quantitative studies (Wright & Dyck, 1984, Schumacher et al., 1993, Gregorio et al., 2012), raised the question of whether initial diagnosis and recurrence were similar or different, they were not able to demonstrate the complexity of the process which both patients and partners engage with, visible in the current study, in terms of making sense of the meaning of recurrence based on their previous experiences.

7.3 Key findings in relation to Theme 2 for Patients: “*Negotiating the place of cancer in one’s life*”

Following a diagnosis of recurrence, patients faced substantial uncertainty and unpredictability of the future. These were related to almost any aspect of their life, including professional responsibilities, their bodies and their future. The life they expected was gone and now they were faced with the new life with cancer. The impact of being faced with diagnosis of an illness was described in sociological literature on chronic illness by Bury and resulted in one of the most known concepts, biographical disruption (1982). This concept was created to both describe and explain the impact of the illness onset (Hubbard and Forbat, 2012). According to Bury, when faced with a diagnosis of an illness, an individual's expected life trajectory and biography are challenged and with that, the body, self and social world (Bury, 1982). Bury's work highlights one of the key consequences of receiving and living with a diagnosis of an illness- that is that core assumptions about the world, the future and the self are challenged. In the current study, biographical flow was disrupted, as for many patients it was no longer possible to continue with daily life as before. This challenge was often magnified by the lack of hope for a change in the future. This was especially visible in the accounts of patients who were not able to have surgery: their faith in the predictable future has been challenged. However, the assumptions about day-to-day life also were challenged for many participants when physical consequences of treatment prevented them from participating in the rhythm of daily activities. Experiencing unpredictable bowel movements, dealing with constantly changing treatment regimes or experiencing new symptoms highlighted the extent of the uncertainty in participants' lives.

The concept of biographical disruption has been used previously in the context of many chronic illnesses such as diabetes (e.g. Lawton et al., 2007), rheumatoid arthritis (Sanders et al., 2002) and recently also cancer. In the context of cancer care, biographical disruption has been discussed in relation to patients with initial diagnosis of colorectal (Hubbard et al., 2010), prostate (Cayless et al., 2010) and lung cancer (Levealahti et al., 2007) but rarely in the context of recurrence. At the time of recurrence, patients seem to experience biographical disruption again. The time between initial diagnosis and recurrence seemed to have an impact on the extent of biographical disruption when faced with a recurrence. For patients who had a short break between initial diagnosis and recurrence, there were limited opportunities for respite. Once again, their assumptions about the world and its order were challenged and as they had limited time to deal with the disruption caused by the initial diagnosis, it seemed to have resulted in the impact of recurrence being magnified.

Dealing with illness has received a lot of attention in health and psychological research and is often talked about in the context of adjustment or coping strategies. Some studies highlighted that these frameworks suggest a more linear process that patients and families go through e.g. adjustment signifying that some resolution has been achieved (Brennan, 2001).

Charmaz (1983) builds on that model, highlighting facing one's mortality as one of the key consequences of facing an illness. Both Bury (1982) and Charmaz (1983) also suggest that when diagnosed with an illness, an individual may either focus on maintaining his or her pre-illness lifestyle and holding on to their previous way of living, or focus on integrating the illness into his or her life and as a result being open about a new life, of which illness is a part. While the first approach may be fuelled by feelings of stigma associated with having cancer, the second one shows the acceptance of the illness by the individual. In psychology, Park et al. (2011) proposed a similar notion and suggested a new term, called illness centrality. In relation to cancer, illness centrality can be defined as "the extent to which one's core self is situated in the context of cancer". Thus, some individuals may distance themselves from cancer while some may incorporate the experience into their identity. It has been found that illness centrality can be negatively associated with well-being, thus suggesting that patients who see their identity evolving around cancer do worse (Park et

al., 2011). Park et al. (2011) suggest that, given the stigmatised image of cancer in society, people with higher illness centrality feel worse, or that those who do not come to terms with their experience remain focused on cancer.

In the current study, patients rarely adopted one way of dealing with the impact of illness. Instead, they seemed to use both strategies, incorporating some aspects of illness into their current life, while holding on to previous ways of living in other aspects. Focusing on cancer, and so potentially demonstrating higher illness centrality, did not always mean higher distress and depended on the meaning of cancer to the individual. Equally, while they made changes to their diet to be able to cope with unpredictable bowel movements, they also focused on the future goals of returning to their pre-cancer activities as soon as possible. Thus, the personal transformation could be, to some extent, a positive result of higher illness centrality and demonstrates the complexity of the potential outcomes for patients in relation to the illness centrality.

Patients not only wanted to return to their previous activities but seemed to need this to regain their sense of self. Bury highlighted that the continuity in the narrative about self is especially important, and hence not being able to continue with previously easily achievable activities may not only mean disruption to people's lives but is also a threat to self (Bury, 1982). Indeed, participants described a diminished sense of self when they were unable to engage in their daily activities.

7.4 Key findings in relation to Theme 2 for Partners: *“Dealing with loss of their previous life and their partner as they knew them”*

Partners also described a variety of changes that they experienced following a patient's diagnosis of recurrence. These seemed to relate to changes to previous day-to-day life as well as either a temporary or ongoing feelings of loss of a partner they used to know.

It may also be important to consider the usefulness of the concept of biographical disruption in the context of partners' experience. To date, this has been rarely recognised, even though a number of studies have highlighted the impact of the cancer recurrence on partners/carers, such as the loss of daily routines, difficulties in attending to one's own needs and a focus on the patient. In the current study, partners also described how their

and their partners' life trajectory was challenged. As a result, similarly to patients, they also seemed to adopt a number of strategies to address challenges to the self. They struggled to incorporate illness into their lives and focused mainly on the impact of losses to their previous life. This was particularly visible when patients had a poorer prognosis. When patients received better news, they seem to be more willing to accommodate illness into their lives, given the hope for the patients' prolonged life. This may suggest that the extent of illness centrality which partners accepted was dependent on the perception of threat of the situation. While in the context of poor prognosis, losses were seen as overwhelming, possibly because of lack of hope, in the context of better news, they were able to be incorporated as part of one's life.

In addition, their relationship with a patient also often underwent dramatic transformation, especially when the patient was suffering from severe side effects. Partners seemed to make choices about protecting patients from their worries. This seemed to challenge the reciprocal nature of the relationship. Kuijer et al., based on the equity theory (Kuijer, Buunk & Ybema, 2001), suggested that when one person becomes ill, it changes whose needs are addressed in the relationship. Kuijer et al. suggest that partners not only have to provide more support by taking on more responsibilities, but also receive fewer rewards by having their needs met to a lesser extent than previously (Kuijer et al., 2001). These changes may lead to patients feeling overbenefited and partners feeling deprived. However, partners may also feel that they do not provide enough care, and consequently feel that they do not sufficiently invest in the relationship. In the current study, partners rarely talked about their own needs and tried to focus on the patient. The focus on the patient was not always easy and they often reflected on the changes to their life as a result of the diagnosis. Although they sometimes were frustrated, these feelings were verbalised cautiously as if they felt that they should not draw attention to their own needs.

Following the diagnosis of cancer, the patient's partner is expected to take on new responsibilities as a carer. Hagedoorn et al. (2000) have recently provided a framework to understand how partners provide support to patients. They highlighted that rather than focusing on the types of support partners provide, for example emotional, practical or informational, we

should consider ways of providing spousal support. They identified three ways of providing support: a) active engagement, which refers to involving patients in discussions about their needs and tailoring support to it; b) protective buffering, which refers to hiding worries, discouraging conversation about patients' concerns and c) overprotection, which refers to focusing on patients' limitations, which may result in providing unnecessary support. They focused on the impact of these different ways of providing support to patients, suggesting that patients who have diminished physical or emotional well-being, may also experience feelings of lack of control and a result may benefit from active engagement, but not benefit from overprotection or protective buffering (Hagedoorn et al., 2000).

While it is important to consider how patients may perceive the support received, the current study also highlights why and to what extent partners may engage in these three types of spousal support. It seems that the way partners provided support differed depending on the level of the patient's physical suffering. The ways they did this, however, were rather complex. In periods of severe suffering, partners seem to provide comprehensive care to patients. When the patient was feeling better, however, partners seemed to struggle to relinquish control and adopt new ways of providing support, such as active engagement, and some continued to provide a high level of care, regarded as overprotection. Protective buffering was adopted as a way of support when partners were particularly afraid of a patient's death.

7.5 Key findings in relation to Theme 3 for Patients: “*Sharing and not sharing the experience of recurrence*”

Patients described difficulties in talking about their experience of cancer recurrence with families and friends. They often had limited opportunity to talk and share issues related to their mortality as these topics were often avoided by families.

Difficulties in discussing the diagnosis of cancer have often been described in the literature in the context of disclosure. Hilton et al. (2009) define cancer disclosure as “the extent to which cancer patients openly discuss with others their diagnosis and thoughts and feeling about their disease” (p.745). While some highlight the benefits of disclosure, some argue that disclosure is not always favourable and talking about things other than

cancer may be preferred by patients in certain contexts, for example focusing on non-cancer topics when staying in the hospital (Hilton et al., 2009). However, it is important to think about the aim of disclosure and to whom people disclose. In the current study, patients wanted to talk about their feelings with their families to be able to deal with unfinished business or to express their concerns, while refraining from talking about illness with the families acted as a way of maintaining normality, similarly to the study described above on avoiding talking about cancer in the hospital. The second factor, to whom patients disclose the diagnosis, is also important. It seems that in the current study, patients were more willing to discuss their concerns with people from within the cancer “circle”, for example, healthcare professionals or fellow cancer patients (both face to face and online), than with partners/family members.

Glaser and Straus also highlighted the importance of the extent of disclosure between people. They coined the terms awareness context, which describes how people who are part of the specific situation are aware of the identity of the other person and the other person’s perception of their own identity (Glaser and Strauss, 1964). They described four different awareness contexts: a) open, which refers to the situation when all parties are acknowledging the situation, e.g. that the person is dying; b) closed awareness context, where one person does not know what the situation is or what the other person knows about the situation; c) suspicion awareness context, which can be described as when one person may suspect what the situation is or how much the other person knows about the situation; and finally d) pretence awareness context, where both persons know what the situation is but choose to pretend that they do not. It seems that in the current study, this was often quite a complex process, with open awareness context achieved in certain areas, while not in others. For example, while the impact of the possibility of death was discussed in relation to children, this was more difficult to discuss between patients and partners themselves. Similarly, patients also chose to adopt pretence awareness when talking about their illness with partners in order to protect their feelings.

Illness centrality (Park et al., 2011) can also play part in the extent to which patients may discuss and share their experience of cancer recurrence. The important point might be whether the illness centrality is shared by other

people. The negative impact may not come purely from seeing cancer as central in one's life (which for some cancer patients with a recurrence could be a more realistic perception), but also from the discrepancy between how the patient and their family see it. The key issue seems to be not only individual differences in each group (patients and partners) but the fact that the problem seems to arise from the discrepancy between patients' and partners' expectations towards their needs and abilities to share their emotions.

Illness centrality and disclosure may also be related to the image of cancer in society, namely being perceived as a life-threatening disease. This issue may be magnified for colorectal cancer, as it is sometimes described as an embarrassing illness (Rozmovits and Ziebland, 2004). This was clear when a need for disclosure was not mirrored by the need to share all aspects of the experience of people, demonstrated by patients' difficulties in discussing problems related to bowels or arranging activities, which needed further consideration. As highlighted by Rozmovits and Ziebland (2004), bowel problems may challenge people's identity as adults as defined by being able to control bodily functions in public. The problems associated with bowel movements were not difficult in themselves, but more importantly in relation to the challenges they posed in the context of socialising or maintaining a professional identity.

7.6 Key findings in relation to Theme 3 for Partners: “*Trying to share the burden of caring*”

Partners' accounts focused mainly on two aspects. Firstly, they often described their practical needs related to the day-to-day caring for the patient. While partners appreciated being able to access advice from the Clinical Nurse Specialist or a GP, they also commented on the negative impact of having to deal with patient's worrying symptoms on their own. Similarly, they described both positive and negative examples of seeking and accessing help from family and friends in sharing the burden of caring. Secondly, partners often described how they struggled for other people to understand their concerns, as they were not part of their reality.

Becoming a carer to a patient with cancer has been recognised as a demanding task. Recently, Stajduhar and colleagues highlighted that family members to patients with an advanced cancer do not just become carers

but rather go through the process of learning to be able to provide care to their loved ones. They identified different ways in which family members learn to become caregivers (Stajduhar et al., 2013). They emphasised that learning process can often resemble a “trial and error” approach, especially if family members lack help from health care professionals or family which may result in not being able to provide the level of care they want. “Actively seeking information” is one of the ways of trying to become more knowledgeable carer. However, it is also a complex process as learning who to seek information from also takes time. Finally, being provided with “guidance by others”, rather than seeking support on their own initiative, can also be a way of the process of learning to become a carer. The current study also highlighted that becoming a carer was sometimes a long process for partners and required different ways of learning. While actively seeking support and receiving guidance from people was appreciated, it was also clear that partners faced some of the challenges of caring on their own and had to adopt “trial and error” approach.

The feeling of loneliness and struggles with being understood by other people as a result of the diagnosis of cancer has been to some extent explored in the current literature. Wells and Kelly (2008) defined loneliness as an “undesirable, negative state arising out of disconnection with other- a severance of the social ties that normally support us through life’s challenges” (p.410). They describe two reasons why cancer patients may feel lonely. Firstly, they may see themselves as different to other people. Secondly, undergoing treatment may in fact mean physical isolation by spending prolonged periods of time in the hospital or by experiencing side effects which prevent them from joining in social activities (Wells and Kelly, 2008). Others provided different conceptualisations of loneliness and distinguished between emotional and social loneliness. Emotional loneliness relates to an absence of a partner or best friend, with close emotional attachment being a key characteristic of this relationship. Social loneliness describes a lack of broader relations and contacts (Weiss, 1973; Deckx et al., 2015). Weiss highlighted that it is not possible to remedy emotional loneliness with having more friends and contacts and, likewise, one cannot fulfil a social void with having a close emotional attachment with one person. While these issues were mainly discussed in relation to patients’ experience, they may also resonate with partners. In the current

study partners seemed to describe both social and emotional loneliness. They faced a number of losses to their relationships due to the presence of cancer in their lives, such as taking on more responsibilities in the household, looking after the patient, as well as providing emotional support to the patient and the family. They lost previous ways of being with other people who tended not to appreciate the demands of caring for a patient.

Partners did not seem to seek contact with other partners of patients with cancer, a strategy which seemed to be beneficial in lessening feeling of loneliness in patients. Also, patients' recovering from surgery or experiencing ongoing side-effects meant that partners also experienced limitations in opportunities to socialise and maintain their previous routines. This was visible in the metaphor used by one of the partners of "life being a prison". It seems that the overwhelming nature of being part of the reality of cancer meant that partners did not want to seek support from people going through the same thing but rather sought respite from their current situation. However, they also wanted their families and friends to gain some insight into their experience to be able to ease the responsibility of caring.

7.7 Dyad experience- similarities and differences

While there were differences and similarities in patients and partners experiences at the group level, there was also a convergence and divergence within dyads.

Within a couple, both patients and partners struggled to make sense of the illness. They all expressed their despair when faced with the diagnosis of recurrence and both patients and partners realised the initial severity of the situation. With time, while some couples continued to share a similar understanding of the prognosis, in some couples there were differences between patients' and partners' views, with partners tending to hold a slightly more optimistic view of the situation. This lack of congruence in patients' and partners' views could create tensions in the relationships. In one couple, the patient's partner did not seem to acknowledge the terminal diagnosis, which resulted in feelings of loneliness in the patient. In contrast, in another couple, it was the partner who seemed to be more overwhelmed by the severity of the situation initially but with better news, was able to regain emotional balance and hope for the future. This in turn enabled him and his partner to regain some normality in their relationship.

There were also differences within couples in the extent to which individuals talked about their experience to each other. While all couples seem to have similar emotional responses to the news of recurrence, they were not necessarily shared with each other. In some couples we could see a clear discrepancy between the individuals' needs. In two couples, patients were not able to talk with their partners about the severity of the situation, and their approaching death. Patients and partners not only struggled to discuss the situation, but also their feelings in doing so. This in turn, prevented them from being able to initiate these discussions. However, not being able to talk about poor prognosis and the future was difficult for patients to deal with as it halted their preparations for death as well as created an emotional distance. On the other hand, there were also instances where both individuals decided to protect each other from difficult feelings and tried to seek other people to share their feelings with. While they were able to find this support in health care professionals, it meant that they struggled to talk to each other about their wishes.

Both patients and partners described at length the impact of the diagnosis of recurrence on themselves, their day-to-day lives, and the other person in the relationship. During periods of severe suffering, couples had to adjust to losses to their previous ways of living, which could create difficulties in the relationship. While within dyads, both patients and partners struggled to accept the losses to their lives, the difficulties in accepting these losses were often a result of patients feeling a burden, and partners being frustrated with their inability to help the patient. In contrast, in one couple the tensions were a consequence of the newly emerged needs of the patient and the difficulties in negotiating these changes in the relationship. With time, the strains in the relationships seemed to also arise in couples where the patient was able to recover physically from the treatment, or with time was able to face an improved prognosis. In these instances, partners often struggled to relinquish control, while patients felt that their partners' attitude was overprotective.

7.8 Implications for clinical practice

The process of making sense of the diagnosis of recurrence is complex and the emotional impact of the patient's diagnosis seemed to be dependent on a number of factors. It is important that health care professionals are aware

that patients and partners' perceptions about what constitutes a successful treatment following the initial diagnosis may be different to theirs. Patients being discharged home and having contact with health care professionals only when attending follow-up appointments may contribute to a patient's perception that they are cancer free, especially when he or she is able to return to previous activities. Information at the time of treatment completion and the subsequent monitoring is important to facilitate partners' understanding of the situation. While some studies have suggested the need for appropriate interventions to deal with fear of recurrence (Taylor et al., 2011), others focused on how we may help patients in identifying recurrence by being aware of possible symptoms (Lewis et al., 2009). It seems that follow-up systems should address both issues: providing reassurance but also drawing patients' attention to the possible risk of the recurrence. This information should be tailored to the situation of a particular patient. This is however, a difficult area in which to achieve balance.

Health care professionals should also take into consideration how they deal with patients at the end of treatment for initial diagnosis as this may have both a positive and negative impact when patients are diagnosed with a recurrence. At the time of the diagnosis of recurrence, patients are no longer novices, both in relation to their condition and the health care system. They have previous experiences, which shape how their current situation is perceived. While to date there has been much debate about both the negative and positive impacts of being a more informed patient, this is mainly in relation to the patient's ability to manage their own condition by developing knowledge and practical strategies (Department of Health, 2001). However, it seems that patients with recurrent disease also develop a different type of expertise at the time of the initial diagnosis, which in turn may have an impact on how they understand and interpret their diagnosis of recurrence. Health care professionals should be aware that previous experiences may provide an inaccurate picture of the current situation, for example when a lesser treatment burden is perceived also as an indication of the lesser severity of the situation. Information needs are also likely to evolve as partners face the changing treatment regimes. Monitoring partners' understanding and tailoring information to their changing needs is also important.

Patients and partners perceived treatment effectiveness and treatment burden as important factors when assessing the severity of the situation, with lack of familiarity with the treatment being particularly challenging. It is important to help patients and partners to deal with this as previous studies indicated that patients and partners who were found to report high levels of uncertainty at time of recurrence were also more distressed. In order to reduce uncertainty and consequently levels of distress, health care professionals could consider how to provide information tailored to each phase of treatment and different treatment options.

A good relationship with health care professionals is very important for both patients and partners. In fact, its significance may even be magnified in the context of limited treatment options, when partners and patients may feel they have been abandoned by health care professionals. It is important that health care professionals are aware of the emotional impact of the diagnosis of cancer recurrence and respond to patients' and partners' needs in a sensitive way.

Ensuring partners' involvement in the care of patients from the outset is also important as they are likely to facilitate the patient's decision making process and to be heavily involved in caring for the patient following their discharge home. In secondary care, health care professionals are largely involved in providing care to the patient while they are receiving treatment and are important in facilitating the transition of patients to home by providing information and practical support. Therefore, it is important that the transition from hospital to home does not mean handing over responsibility to the partner but rather supporting them in being able to facilitate this transition, while providing access to specialist support if needed. Health care professionals should provide partners with knowledge and skills so they feel confident in helping patient when transferred home. Partners should be provided with verbal and written information at the time of patient's discharge home. Having access to ongoing advice from the Clinical Nurse Specialist could also be a good solution.

Patients and partners often struggled to discuss their difficult feelings with each other. They often sought support from other people, especially health care professionals or fellow cancer patients. While this was clearly beneficial for them, it also created emotional distance in the relationship

between patient and partner. Health care professionals should be alert to these difficulties in communication and their impact on both patients and partners. As Clinical Nurse Specialists often provide emotional support to patients, they would be well placed to help patients or partners initiate the difficult topics during the consultation, which could then be discussed between a patient and their partner outside of the hospital. This could help to facilitate discussions about difficult topics in couples by first identifying where the potential areas of difficulties are and secondly by trying to help couples to find ways of talking about them.

While it is important that the individual psycho-social needs of both patients and partners are met, it is also crucial to attend to the needs of the patient and their partner as a dyad. An acknowledgement that cancer happens to a couple, not only to individuals, is an important step in meeting this need. Facing a diagnosis of cancer could be an important stage in not only each individual's life, but also for the relationship, which may hinder or facilitate an intimate bond. Health care professionals should be aware of each individual's needs but also their needs within relationship as a whole.

Finally, while some patients and partners were satisfied with the support received from family and friends, others found it difficult to discuss the diagnosis and prognosis with others and did not feel well supported. It is important that health care professionals recognise these difficulties so they can help patients and their partners to access appropriate support. In line with the previously discussed theory of equity, it may also be beneficial for partners to have access to services which can provide respite from day-to-day caring for patients. While this support would not come directly from the patient, it may facilitate restoring partners' personal resources to deal with the situation. This may be particularly helpful for partners caring for patients for prolonged periods of time.

7.9 Strengths and limitations of the current study

This is the first study which explores longitudinally the experiences of patients and partners of patients at the time of recurrence. It fills an important gap in the literature, highlighting key challenges that patients and partners of patients face at this crucial stage in their journey.

The majority of previous studies looking at the experiences of patients with recurrence have focused on breast and ovarian cancer. Only one previous study explored the experiences of patients with colorectal cancer recurrence (McCahill & Hamel- Bissell, 2009). This study included only patients who were offered surgery following liver metastasis, and as such provides a limited insight into the experience of colorectal cancer recurrence. Studies exploring partners' experiences of recurrence were even scarcer, with the majority of these focusing on levels of distress. Finally, no previous study has explored the experiences of patients and partners of patients over time. The current study demonstrated that experiences and needs of patients may evolve over time and therefore it is useful to adopt a longitudinal perspective.

It is also important to note that the majority of participants were retired or near retirement, with only one couple having young children. While all patients seemed to experience disruption to their previous lives and ways of being, the nature of the challenges they faced was closely related to the life stage of each individual. When faced with an illness, the developmental tasks related to a particular life stage of both an individual and family, might not be able to be fulfilled. For example, younger participants in the early to middle adulthood faced the challenge of cancer at the time in their life when bringing up children is often considered a key responsibility (Veach, Nicholas, Barton, 2002). Also, all couples were in heterosexual relationships and it is important to understand the unique needs of same-sex couples.

Similarly, although the recruitment took place in four different NHS Trusts serving ethnically diverse populations, all participants were White and British. Studies exploring the experiences of ethnic minorities are crucial to gain an understanding of potential cultural factors which may have an impact on how individuals understand and cope with the diagnosis of advanced illness.

Studies employing IPA usually involve small homogenous samples to allow comparison of similarities and differences between individuals. The current study adopted a broad definition of homogeneity: for patients, this meant anyone receiving a diagnosis of a recurrence of colorectal cancer in the previous year and for partners this meant the individual recognised as the

primary partner of someone who had been diagnosed with a recurrence in the previous year. As a result, participants differed in terms of age, background, and treatment received. While this reflected the clinical variability of colorectal cancer recurrence, it also made the analysis more challenging. Similarly, due to difficulties in recruitment described in chapter 4, the time between diagnosis and first interview (and consequently the second interview) varied across participants. However, given the ideographical nature of IPA, longitudinal analysis within case was the initial focus of analysis, allowing the capture of potential changes within individuals before moving on to comparisons across cases.

The sample for this study was a convenience sample of patients recruited from the NHS and social media. NHS participants came from two NHS sites. It is important to note that participants recruited via the internet may be very different to the rest of the study population (Reed et al., 2009, Casañas i Comabella and Wanat, 2014).

7.10 Recommendation for further research:

Given the importance of the initial diagnosis when making sense of recurrence it would be beneficial to explore the experiences and understanding of patients prospectively, starting with the initial diagnosis. A prospective longitudinal qualitative study (rather than retrospective as the current one) would allow the exploration of potential changes in patients' and partners' understanding of cancer as well as aims of follow-up and monitoring. However, this would be time- and resource- intensive.

While previous studies explored the differences of levels of distress between initial diagnosis and recurrence, they rarely explored the impact of potential factors influencing different outcomes for people with recurrence. The current study demonstrated that, for example, treatment type may have an impact on the level of distress experienced by patients and partners. Further quantitative studies could explore the potential difference in level of distress in specific groups of patients and their partners (e.g. patients who were offered surgery or chemotherapy only, as the prognosis may moderate the impact of recurrence).

The current study highlighted that the internet can be a source of social support for patients at the time of recurrence. Previous studies have shown

that the internet is a growing source of information and can affect patient-doctor communication (Ziebland, 2004, Ziebland et al., 2004). Other studies, mainly in relation to breast cancer, also highlighted the benefits of online groups, particularly for patients living in remote areas, or not being able to participate in face-to-face groups because of their health status (Winzelberg et al., 2003). It would be interesting to explore the characteristics of people who do seek support on the internet and the potential challenges and benefits of doing so at the time of colorectal cancer recurrence. For patients with deterioration in physical functioning either because of treatment or problems with bowels, it could potentially be one way of reducing social isolation.

It would also be beneficial to explore the perspectives of health care professionals caring for people with colorectal cancer recurrence. Little is known about the challenges associated with caring for patients with bowel cancer recurrence from the perspective of health care professionals. Evidence is scarce as the majority of studies focus on the patient's experience of recurrence. Also, as described earlier, these relate to ovarian or breast cancer and it is unclear what the challenges associated with bowel cancer are.

7.11 Reflections on the research process

As described in Chapter 4, I encountered major difficulties in recruiting participants into my study. Being an academic researcher meant that I was coming as an "outsider" to the health care system and it took me time to develop a good relationship with clinical teams.

Difficulties in recruitment were also partly because of the sensitive nature of my research, and partly due to a reluctance of health care professionals to approach potential participants. There has been much discussion in recent years of the value of involving patients with poor prognosis in research, mainly in relation to palliative care. Concerns have been raised that we should not take valuable patient time which they could be spending with their families, or that we could be causing additional distress by discussing sometimes painful topics (Barnett, 2001). At the same time, concerns have been raised that not providing participants with an opportunity to take part in research is a way of denying their autonomy (Addington-Hall, 2002). In my study, I felt that participants valued the opportunity to discuss their

experience in detail and in fact, perceived the interviews as helpful in making sense of their situation.

Although I had had previous experience of doing cancer care research, this was mainly in the context of people using psychological services in a cancer centre. That group of patients was usually physically quite well, as they had completed their initial treatment and the majority were long-term survivors. This study was very different and I felt that patients in this study were more vulnerable as they were experiencing another diagnosis. Witnessing physical suffering, not only described by patients, but also clearly visible (for example, when the patient was lying in bed), was difficult for me initially and I reflected on how this may have influenced my interactions with patients. Similarly, although partners were not suffering physically, they often described painful, and often for me moving, experiences of dealing with cancer recurrence. Listening to their experiences rather than feeling sympathy was something which, on occasion, I found difficult to achieve. Before the second interview, I often found myself wondering how the patient and partner had been and was worried that they may have deteriorated. I found that keeping a reflective journal not only for the purposes of analysis but also as a way of monitoring my own feelings and managing distress was useful.

Conducting a longitudinal study allowed me to build rapport with participants and I felt that with some, it led to a greater disclosure. However, I also tried to make sure that the participants understood the purpose of our meeting to be research in order to create clear boundaries. As participants on a number of occasions commented that they found talking to me as beneficial, I usually responded by highlighting that they helped me by contributing to my PhD. The issue of research having similarities with therapy has been raised previously (e.g. Hart & Crawford-Wright, 1999). Hart and Crawford-Wright drew attention to the fact that if someone was to eavesdrop on a research interview, they would not always be able to say whether this was therapy or research. They highlight similarities such as listening to, interpreting and making sense of participant's experience. However, they also underline the key difference in that in the research interview there is a different power dynamic, as it is the participant who is helping the researcher not the other way round (like in

the therapeutic encounter). I found that understanding this distinction helped me to maintain clear boundaries with participants.

7.12 Summary of thesis

This thesis has explored the experiences of a diagnosis of colorectal cancer recurrence from the perspective of patients and partners of patients. A meta-ethnography and a literature review provided some insight into the experiences of patients and partners when faced with cancer recurrence, but they also highlighted the paucity of studies exploring the experiences of partners at time of recurrence in general, and particularly, the experiences of patients with bowel cancer recurrence.. This study revealed that the initial diagnosis was an important reference point for patients in trying to make sense of the diagnosis of recurrence. Specifically, previous experiences and understanding of treatment was particularly important in how participants perceived their current situation. It also became apparent that while patients and partners valued support from health care professionals as well as family and friends, this was not always available and highlighted difficulties in sharing the experience of recurrence with people. Partners also described their challenges of sharing the burden of caring for patients with both family and health care professionals, with loneliness being one of the key difficulties. Finally, the study also highlighted that participants experienced a number of changes to their lives. The impact of that often depended on the severity of symptoms experienced by patients.

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Appendices

Appendix 1: Studies included in the meta-ethnography

Appendix 2: Topics guides

Appendix 3: Approval letters

Appendix 4: Invitation Letter

Appendix 5: Patient Information Sheet

Appendix 6: Reply Slip

Appendix 7: Partners Information Sheet

Appendix 8: Consent Form

Appendix 9: Article in press

Appendix 1: Studies included in the meta-ethnography

Study and Woods et al. (2004) Coding (K=Key paper, SAT- satisfactory, FF- fatally flawed IRR -Irrelevant)	Country setting	Sample N (age, gender and cancer site: primary)	Time since the initial diagnosis	Length of time with diagnosis of recurrence	Methods of data collection	Methods of data analysis	Aim
Chunklestskul et al. (Chunlestskul et al., 2008a) K	Canada	N= 5 women, 44-72 years breast	16-18 years	2-6 years	Open –ended interviews on two occasions	Phenomenological approach (not defined)	To explore the lived experiences of women with metastatic breast cancer in preparation for their death

Chunklestskul,et al. (Chunlestskul et al., 2008b)	Canada	N= 5 women, 44-72 years breast	16-18 years	2-6 years	Open –ended interviews on two occasions	Phenomenological approach (not defined)	To examine enabling and impeding factors in death preparations
K							
Coward and Wilkie (Coward and Wilkie, 2000)	USA	N=20, 10 women and 10 men, 26-73 years, breast, lung, bladder, prostate, kidney and thyroid	1-13 years	1 month- 8 years	Semi-structured interviews	Not specified	To explore gender differences in experience of metastatic bone pain
SAT							

Dooks et al. (Dooks et al., 2012) SAT	Canada	N=9, 1 woman and 8 men, 60-75 years oral	-----	6-12 months	In depth interviews	Interpretative descriptive approach by Sally Thorne (1997)	To describe patients' experience of reintegrating into community following surgery
Ekwall et al. (Ekwall et al., 2007) SAT	Sweden	N=12 women, 50-74 years ovarian	1-5.7 years (Mean=2.8)	5-10 months	Interviews	Phenomenological method (Giorgi and Giorgi, 2003)	To explore experiences of women diagnosed with recurrent ovarian cancer and its impact on daily lives

Ekwall et al. (Ekwall et al., 2011)	Sweden	N=12 women 50-74 years (Median=57.5) ovarian	1-5.7 years	5-10 months	Interviews	Qualitative content analysis: Grundheim and Lundman (2004)	To explore what women with recurrent ovarian cancer perceive as important in their communication with the health care team
K							
Ekwall et al. (Ekwall et al., 2014)	Sweden	N=4 women, 46-69 years, ovarian	6-10 years	3 years and 5 years	Open- ended interviews on two occasions (3 and 5 years after recurrence)	Phenomenological approach (Giorgi, 2009)	To explore the phenomenon of living with recurring ovarian cancer
K							

Elit et al. (Elit et al., 2010)	Canada	N= 26 women, 44-77 years ovarian,	6-36 months	2 months	Semi-structured interviews;	Unspecified Content analysis;	To explore treatment decision making process and experiences of women with recurrent ovarian cancer
SAT							
Griffiths et al. (Griffiths et al., 2008)	UK	N=9, 6 women and 3 men, 63-85 years, oral	-----	1-8 weeks	Semi-structured interviews	Grounded theory approach	1)To investigate the psychosocial responses of patients with oral cancer recurrence; 2) To highlight the key psychological issues
K							

Howell, Fitch and Deane (Howell et al., 2003)	Canada	N=12 out of 18 women had recurrence; ovarian	-----	-----	Semi-structured telephone interviews	Not specified; coding scheme developed and used by all authors	To explore the experience of women with ovarian cancer
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SAT

Maher and De Vries (Maher and De Vries, 2011)	UK: London	N=8, 5 women and 3 men, 48-74 years, myeloma	-----	-----	Unstructured interviews	Theoretical framework of Hermeneutic phenomenology; thematic content based on method of Colaizzi (1978)	To explore how the experience of living with relapsed myeloma had affected the quality of life of patients
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SAT

Mahon and Casperson (Mahon and Casperson, 1997)	USA	N=20, 26-72 years (Mean=54); type not specified	8-94 months, (Mean=37 months)	30 days	Unstructured and semi-structured interviews	Not specified; Software used	To describe the meaning of a recurrence of cancer to the patient and possible differences between initial diagnosis and recurrence
SAT							
McCahill and Hamel- Bissell (McCahill and Hamel-Bissell, 2009)	USA	N=12; 5 women and 7 men, 45-75 years, colorectal	-----	-----	In depth semi-structured interviews	Phenomenological approach; Three step analysis using Colaizzi method (1978)	To explore the lived experience of patients who experienced surgery for CRC liver metastasis

SAT

Misra et al. (Misra et al., 2013)	Canada	N=15, 12 women and 3 men); thyroid	1-21 years (Median= 5)	11-79 months (Median=24)	Semi-structured interviews	Unspecified thematic analysis combined with grounded theory	To explore the individual patient experiences relating to diagnosis and surgical treatment of loco-regional recurrence of thyroid cancer
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Rose, Spencer and Rausch (Rose et al., 2013)	USA	N=17, ovarian	-----	-----	Interviews	Phenomenological method by Colaizzi (1978)	To explore how patients with ovarian cancer recurrence experience humour
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IRR

Sarenmaln et al. (Sarenmalm et al., 2009)	Sweden	N= 20 women, 55-81 years; breast	Median= 68 weeks	2 weeks- 24 months	In depth interviews	Grounded theory: Glaser and Strauss 1967 and Glaser (1978)	To explore the main concerns of women with breast cancer recurrence and how they deal with breast cancer recurrence
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K

Step and Ray (Step and Ray, 2011)	USA	N=30 women, 42-84 years, breast, lung, gynaecological and head and neck	7.3 years	-----	Interviews	Thematic analysis (not specified)	To explore patients' experience of communication at time of initial diagnosis and recurrence
K							
Vilhauer (Vilhauer, 2008)	USA	N=14 women; Mean age: 51.6 years , breast	-----	Mean =25.8 months	Telephone interviews	Content analysis	To investigate the experiences of women with metastatic breast cancer
SAT							

Appendix 2: Topics guides

Topic guide- patients

Time 1: After the diagnosis of recurrence

Starting with the questions about their experiences with cancer from the beginning (initial diagnosis):

What happened before the recurrence

- Feelings and thoughts about initial diagnosis
- Treatment received
- Finding new symptoms/acting on it
- Suspecting cancer

What happened at the recurrence

- Who told them/plan of action
- Feelings and thoughts about the recurrence
- How they and the family reacted

Impact of cancer recurrence on day to day life:

- Physical impact
- Impact on social activities
- Impact on relationships
- Impact on work/occupational life

Impact on the individual

- Emotional impact
- Thoughts/plans about the future
- Understanding of cancer/what it means

Information and supportive care needs

- What is being provided at the moment
- Sources of support
- What is useful/not so useful about the support at the moment

Time 2: after treatment completion

Starting with a question about what has happened in their lives in relation to cancer since the interviewer last saw them

Treatment received

- What treatment they received
- What they thought about the treatment
- What was the experience like for them
- Who supported them

Impact of cancer recurrence on day to day life:

- Physical impact
- Impact on social activities
- Impact on relationships
- Impact on work/occupational life

Impact on the individual

- Emotional impact
- Thoughts/plans about the future
- Understanding of cancer/what it means

Information and supportive care needs

- What is being provided at the moment
- Sources of support
- What is useful/not so useful about the support at the moment

Topic guide- partners

Time 1: After the diagnosis of recurrence

Starting with the questions about their experiences with cancer from the beginning (initial diagnosis):

What happened before the recurrence

- Feelings and thoughts about initial diagnosis of their spouses/partners
- Finding new symptoms/acting on it
- Suspecting cancer

What happened at the recurrence

- Feelings and thoughts about the recurrence
- How they and the family reacted

Impact of cancer recurrence on day to day life:

- Impact on social activities
- Impact on relationships
- Impact on work/occupational life

Impact on the individual

- Emotional impact
- Thoughts/plans about the future
- Understanding of cancer/what it means

Information and supportive care needs

- What is being provided at the moment
- Sources of support
- What is useful/not so useful about the support at the moment

Time 2: after treatment completion

Starting with a question about what has happened in their lives in relation to cancer since the interviewer last saw them

Treatment received

- What treatment their partner's received
- What they thought about the treatment
- What was the experience like for them
- How do they feel about it

Impact of cancer recurrence on day to day life:

- Physical impact
- Impact on social activities
- Impact on relationships
- Impact on work/occupational life

Impact on the individual

- Emotional impact
- Thoughts/plans about the future
- Understanding of cancer/what it means

Information and supportive care needs

- What is being provided at the moment
- Sources of support
- What is useful/not so useful about the support at the moment

Appendix 3: Approval letters



Health Research Authority

NRES Committee South Central - Oxford B

Bristol REC Centre
Whitefriars
Level 3, Block B
Lewin's Mead
Bristol
BS1 2NT

Telephone: 0117 342 1333
Facsimile: 0117 342 0445

21 May 2012

Miss Marta Wanat
PhD Research Student
Oxford Brookes University
Department of Clinical Health Care
Jack Straws Lane, Marston
Oxford
OX3 OFL

Dear Miss Wanat

Study title: Experiences of patients with a recurrence of colorectal cancer and spouses/partners: a longitudinal qualitative study
REC reference: 12/SC/0214
Protocol number: N/A

Thank you for your letter of 17 May 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		27 March 2012
Evidence of insurance or indemnity		08 July 2012
GP/Consultant Information Sheets	3	14 May 2012
Investigator CV	Marta Wanat	27 March 2012
Letter from Sponsor		21 March 2012
Letter from Sponsor		15 May 2012
Letter of invitation to participant	3	14 May 2012
Other: Cv for Mary Boulton		26 March 2012
Other: Letter from Funder		20 March 2012
Other: CV for Eila Watson		26 March 2012
Other: CV for Prof Bee Wee		26 March 2012
Other: Offer Letter for PhD studentship-proof of funding		20 June 2011
Other: Letter from faculty ethics committee- peer review	1	21 March 2012
Other: Participant demographic form	2	02 March 2012
Other: Lay Research Summary	2	14 May 2012
Other: Reply Slip	2	02 March 2012
Other: Topic Guide- Patients	2	14 May 2012
Other: Topic Guide- Partners	2	14 May 2012
Other: Participants Demographics	3	14 May 2012
Participant Consent Form	3	14 May 2012
Participant Information Sheet: Partners/spouses	2	01 March 2012
Participant Information Sheet: Patients	3	14 May 2012
Protocol	3	14 May 2012
Questionnaire: Hospital Anxiety and Depression Scale		
REC application	3.4	30 March 2012
Referees or other scientific critique report	Scientific Peer	20 March 2012

	Review	
Response to Request for Further Information		17 May 2012
Summary/Synopsis	1, Lay Summary of Research	25 January 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

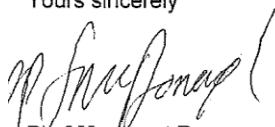
You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/SC/0214	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely



Prof Margaret Rees
Chair

Email: scsha.oxfordRECB@nhs.net

Enclosures: "After ethical review – guidance for researchers" [Emailed]

Copy to: Hazel Abbott heabbott@brookes.ac.uk
Heather House heather.house@admin.ox.ac.uk



Health Research Authority

NRES Committee South Central - Oxford B

Bristol Research Ethics Committee Centre
Whitefriars
Level 3, Block B
Lewin's Mead
Bristol
BS1 2NT

Tel: 0117 342 1333
Fax: 0117 342 0445

26 March 2013

Miss Marta Wanat
PhD Research Student
Oxford Brookes University
Department of Clinical Health Care
Jack Straws Lane, Marston
Oxford
OX3 0FL

Dear Miss Wanat

Study title: Experiences of patients with a recurrence of colorectal cancer and spouses/partners: a longitudinal qualitative study
REC reference: 12/SC/0214
Protocol number: N/A
Amendment number: Substantial Amendment: Amendment 4, 02.03.2013
Amendment date: 02 March 2013
IRAS project ID: 95592

The above amendment was reviewed the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Protocol- Summary of Changes		
Reply Slip	5	02 March 2013
Letter of invitation to participant	5	02 March 2013
Participant Information Sheet	5	02 March 2013

A Research Ethics Committee established by the Health Research Authority

Notice of Substantial Amendment (non-CTIMPs)	Substantial Amendment: Amendment 4, 02.03.2013	02 March 2013
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Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

12/SC/0214:	Please quote this number on all correspondence
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Yours sincerely



Prof Margaret Rees
Chair

E-mail: NRESCommittee.SouthCentral-Oxfordb@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Heather House
kari.shepherd@admin.ox.ac.uk

Hazel Abbott
heabbott@brookes.ac.uk

NRES Committee South Central - Oxford B

Attendance at Sub-Committee of the REC meeting on 18 March 2013

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Mr Robert King	Retired University Lecturer (Philosophy)/ Committee Vice Chair	Lay Plus
Prof Margaret Rees	Retired Consultant / Reader Emeritus in Gynaecology / Committee Chair	Expert

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Mrs Siobhan Bawn	Co-ordinator

NRES Committee South Central - Oxford B

Bristol Research Ethics Committee Centre
Whitefriars
Level 3, Block B
Levin's Mead
Bristol
BS1 2NT

Tel: 0117 342 1333
Fax: 0117 342 0445

26 March 2013

Miss Marta Wanat
PhD Research Student
Oxford Brookes University
Department of Clinical Health Care
Jack Straws Lane, Marston
Oxford
OX3 0FL

Dear Miss Wanat

Study title: Experiences of patients with a recurrence of colorectal cancer and spouses/partners: a longitudinal qualitative study
REC reference: 12/SC/0214
Protocol number: N/A
Amendment number: Substantial Amendment 5, 07.03.2013
Amendment date: 07 March 2013
IRAS project ID: 95592

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The Committee found there to be no items of ethical concern.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Summary of Changes to the Protocol		
Reply Slip- Postal Invite	1	07 March 2013

A Research Ethics Committee established by the Health Research Authority

Letter of Invitation to participant	1, Postal- Invite	07 March 2013
Participant Information Sheet: Partner	1	07 March 2013
Participant Information Sheet: Patient	1	07 March 2013
Notice of Substantial Amendment (non-CTIMPs)	Substantial Amendment 5, 07.03.2013	07 March 2013

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

12/SC/0214:	Please quote this number on all correspondence
-------------	--

Yours sincerely



Prof Margaret Rees
Chair

E-mail: NRESCommittee.SouthCentral-Oxfordb@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Heather House
Karl.shepherd@admin.ox.ac.uk

Hazel Abbott
hazabbott@brookes.ac.uk

NRES Committee South Central - Oxford B

Attendance at Sub-Committee of the REC meeting on 18 March 2013

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Mr Robert King	Retired University Lecturer (Philosophy)/ Committee Vice Chair	Lay Plus
Prof Margaret Rees	Retired Consultant / Reader Emeritus in Gynaecology / Committee Chair	Expert

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Mrs Siobhán Bawn	Co-ordinator

NRES Committee South Central - Oxford B

Bristol Research Ethics Committee Centre
Whitefriars
Level 3, Block B
Lewin's Mead
Bristol
BS1 2NT

Tel: 0117 342 1333
Fax: 0117 342 0445

01 February 2013

Ms Hazel Abbott
Oxford Brookes University
Research Ethics Lead, School of Health and Social Care, Jack Straw Lane, Headington
Oxford
OX3 0FL

Dear Ms Abbott

Study title: Experiences of patients with a recurrence of colorectal cancer and spouses/partners: a longitudinal qualitative study
REC reference: 12/SC/0214
Protocol number: N/A
Amendment number: Substantial Amendment: 3, 10/01/2013
Amendment date: 10 January 2013
IRAS project ID: 95592

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The Committee found there to be no items of ethical concern.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Study Website - Screenshot	1	20 December 2012
Advertisement	1, Online Advert	20 December 2012
Participant Information Sheet: Partner - Online Study	1	20 December 2012

A Research Ethics Committee established by the Health Research Authority

Participant Information Sheet: Patient - Online Study	1	20 December 2012
Notice of Substantial Amendment (non-CTIMPs)	Substantial Amendment: 3, 10/01/2013	10 January 2013
Covering Letter	1	20 December 2012

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

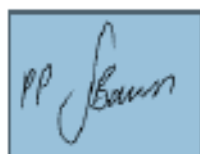
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

12/SC/0214:	Please quote this number on all correspondence
-------------	--

Yours sincerely



Prof Margaret Rees
Chair

E-mail: NRESCommittee.SouthCentral-Oxfordb@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Ms Heather House
Karl.shepherd@admin.ox.ac.uk

Miss Marta Wanat
marta.wanat-2011@crookes.ac.uk

NRES Committee South Central - Oxford B

Attendance at Sub-Committee of the REC meeting on 31 January 2013

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Mr Robert King	Retired University Lecturer (Philosophy)/ Committee Vice Chair	Lay Plus
Prof Margaret Rees	Retired Consultant / Reader Emeritus in Gynaecology / Committee Chair	Expert

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Mrs Siobhan Bawn	Co-ordinator

Appendix 4: Invitation Letter

Dear ...

Invitation to take part in a research study: A study looking at the experiences of bowel cancer patients and spouses/partners when they have been told that the cancer has come back.

I am writing to you to ask if you may be interested in taking part in a research study which is looking at the experiences of patients with a recurrence of bowel cancer. The spouses / partners of patients (where applicable) are also invited to take part. The aim of the study is to understand what sort of information, advice and support would best help patients and their families at this time, to inform the development of future services.

The study is being carried out by Oxford Brookes University and has been approved by a National Research Ethics Committee. Taking part would mean agreeing to an interview with the study researcher some time over the next couple of weeks and then again a few months later (if you still wanted to take part at that time). You would also be asked to provide some background information and fill in a short questionnaire regarding how you feel at the moment. Please find enclosed a Study Information Sheet which will provide you with more detail about this study.

If you and / or your spouse / partner (if applicable) are interested in hearing more about the study, please indicate this by ticking the box on the attached Reply Slip and post it to the researchers in the pre-paid envelope at your earliest convenience. If only one of you would like to take part that is fine. The study researcher will then make contact directly to further discuss the study.

Taking part in this study is entirely voluntary. We would like to reassure you that everything you tell us will be treated in the strictest confidence. Your medical care will not be affected whether you decide to take part in this study or not. Also, the research team will not be passed any information about you unless you consent to take part in the study. If you have any questions about the research please telephone Marta Wanat who is leading this research at Oxford Brookes University, on 01865 482745.

Thank you very much for taking time to read this letter.

Yours sincerely,

[Insert clinician's name]

Research Team: Miss Marta Wanat (Chief Investigator), Professor Eila Watson, Professor Mary Boulton and Professor Bee Wee

Appendix 5: Patient Information Sheet



Participant Information sheet for Patients

Experiences of bowel cancer patients and spouses/partners when they have been told that the cancer has come back

Introduction

We would like to invite you to take part in our research study. Before you decide whether you would like to participate, please read the information below about this study. We hope that it will answer some questions you may have and help you to make your decision. Thank you for taking time to read this Information Sheet.

Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1:

What is the aim of the study?

The aim of the study is to understand the experiences of patients whose bowel cancer has come back (recurred) and their spouses/partners (if applicable). We want to explore what it is like for you to have a recurrence of colorectal cancer and what information, advice and support you feel would be helpful. We will be able to use the findings from this study to inform the development of future services

Why am I being invited to take part in the study?

We are inviting individuals who have had a recurrence of bowel cancer in the last year and /or their spouse/partner to take part.

What would taking part involve?

Taking part would involve being interviewed by Marta Wanat, a researcher from Oxford Brookes University. She would ask you some questions regarding your experiences and the impact of having a recurrence of colorectal cancer on you, your family and everyday life. We would also like you to provide some background information and fill in a questionnaire about how you feel at the moment. If you agree, Marta would like to interview you twice. Ideally the first interview would take place in the next week or so, and then she would like to interview you a few months later. The interview would take place in the venue of your choice, for example your own home or another location of your choice. All travel expenses would be paid. Each interview would take approximately one hour. With your permission, the interviews would be recorded so they can be written up (i.e. typed) later. This will mean we will be able to capture everything in your own words. Only members of the research

team at Oxford Brookes University would have access to this information and it would be treated in strict confidence.

If you agree to participate, we would like to inform your GP that you are taking part in this study. In that case, we would ask for your GP details on the day of your interview.

If you have one, we would like you to invite your spouse/partner to take part in this study and ask if you would be willing to also pass the Information Pack for Partners and Reply slip to them. We would like to interview you separately if possible. If you do not wish to be involved in the study, your spouse/partner (if applicable) will be welcome to participate in the study. Likewise, if your spouse/partner does not wish to be involved, you are welcome to participate.

Do I have to take part?

Taking part in this study is entirely voluntary and it is up to you to decide if you want to take part. If you do decide to take part you would be given this Information Sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect the standard of care you receive.

Are there any benefits or risks of taking part in the study?

Some people may find it upsetting to talk about their experiences. You are free to tell the interviewer if there are any questions you would prefer not to answer. You can also withdraw from the study at any time without giving any reason. Your care will not be affected in any way.

There are no direct benefits for you taking part, although many patients do find talking to an independent researcher about their experiences helpful. However, we hope that the findings from this study will help us to inform future clinical practice and improve the way the services are delivered.

Part 2

What will happen to the information I give you?

All the information which you give us will be kept strictly confidential and will not be passed to anyone else. Only members of the research team at Oxford Brookes University will have access to the information and it will not be shared with the members of your clinical team. Your name and address will be removed from any data. What you say during the interview will not be passed to anyone outside the Research Team. All quotes from the interviews used in future publications will not have your name on it. Our procedures for the handling, processing, storage and destruction of all study data will comply with the Data Protection Act 1998.

What will happen to the results of the study?

The results from the study will be used to improve the care for patients with colorectal cancer recurrence and their spouses/partners. The study will help us understand what issues people face at this stage of cancer and how we can best help them.

We plan to publish the results of the study in a national journal. You are welcome to receive a summary of the results if you wish to. No individual will be recognisable in any part of the write-up or article, however quotes from participants will be used to illustrate and explain points. Any quotes used will be completely anonymous; that is they will not have your name on them or include any information which would suggest the quote had been made by you.

Who is organising the study?

The study is organised by Marta Wanat, a Research Student at Oxford Brookes University. It is a collaboration between Oxford University Hospitals NHS Trust, Birmingham University Foundation Trust and Royal Berkshire University Hospitals Trust.

What do I do now?

You do not have to do anything. Marta will contact you in a few days time to answer any questions you may have and talk about the study in more detail. If you are still interested in taking part then, she will arrange a convenient time for your interview.

If applicable and you would like your spouse/partner to know more about the study please pass to him/her the Information Pack for Partners and Reply Slip. If your spouse/partner does not wish to take part, you are still welcome to take part in the study.

What will happen if I do not want to continue with the study?

You can withdraw from the study at any time. Marta will contact you again before the second interview to check whether or not you are still happy to take part.

What if there are any problems?

If you have any concerns about any aspect of this study, please contact the Research Ethics Lead in the Faculty of Life Sciences at Oxford Brookes University. Her contact details are:

Ms Hazel Abbott
Faculty of Life Sciences
Oxford Brookes University
Jack Straws Lane
Oxford OX3 OFL
Tel: 01865 482639

LREC name: Experiences of colorectal cancer recurrence Patient Information Sheet- online study Version 1/20.12.2012
FREC study number: 2011/11
South Central-Oxford REC B study number: 12/SC/0214

3

Who has reviewed the study?

The study was reviewed by Oxford Brookes University and a National Research Ethics Committee.

What if something goes wrong?

Given the nature of this study, it is highly unlikely that anything will go wrong. However, if you feel you have been harmed in some way by participating in the study, you may have grounds for legal action for compensation against Oxford Brookes University.

Further information and contact details

If you would like any further information, or have any further questions concerning this research study you are encouraged to contact the Researcher, Miss Marta Wanat on 01865 485278 (marta.wanat-2011@brookes.ac.uk) or members of the research team: Professor Eila Watson on 01865 482665 (ewatson@brookes.ac.uk) or Professor Mary Boulton on 01865 485298 (mgboulton@brookes.ac.uk). Should this study have raised any particular issues for you in relation to cancer you may wish to contact your GP practice or Macmillan Cancer Support (macmillan.org.uk) on 0808 808 00 00 and/or your local Maggie's Centre, (www.maggiescentres.org). Both are organisations which provide information and support for people with cancer and their family members / carers. Should you wish to discuss taking part in research in general you may wish to contact Macmillan Cancer Support (macmillan.org.uk) on 0808 808 00 00 and/or your local Maggie's Centre, (www.maggiescentres.org).

Appendix 6: Reply Slip



REPLY SLIP

Research Study: Experiences of patients with a recurrence of colorectal cancer and their spouses/partners

I would be interested in hearing more about the above research study and happy for the researcher to contact me directly to tell me more.

Your name: _____

Your preferred telephone number: _____

Email: _____

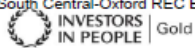
Please indicate below if you are a patient who has a recurrence of colorectal cancer or the spouse / partner of a patient, and also your gender.

Are you: Patient Spouse / partner

Are you: Male Female

LREC study name: Experiences of colorectal cancer recurrence Reply Slip
FREC study number: 2011/11
South Central-Oxford REC B study number: 12/SC/0214

Version 5/02.03.2013



www.brookes.ac.uk

Appendix 7: Partners Information Sheet



Participant Information sheet for Spouses/Partners

Experiences of bowel cancer patients and spouses/partners when they have been told that the cancer has come back

Introduction

We would like to invite you to take part in our research study. Before you decide whether you would like to participate, please read the information below about the project. We hope that it will answer some questions you may have and help you to make your decision. Thank you for taking time to read this information.

Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1:

What is the aim of the study?

The aim of the study is to understand the experiences of patients whose bowel cancer has come back (recurred) and, where applicable, their spouses/partners. We want to explore what it is like for you to have a partner/spouse with a recurrence of colorectal cancer and what information, advice and support you feel would be helpful both for you and your spouse/partner. We will be able to use the study findings to inform the development of future services.

Why am I being invited to take part in the study?

We are inviting individuals who have had a recurrence of bowel cancer in the last year and /or their spouse/partner to take part.

What would taking part involve?

Taking part would involve being interviewed by Marta Wanat, a researcher from Oxford Brookes University. She would ask you some questions regarding your experiences and the impact of having a spouse/partner with a recurrence of colorectal cancer on you, your family and everyday life. We would also like you to provide some background information and fill in the questionnaire about how you feel at the moment. If you agree, Marta would like to interview you twice. Ideally the first interview would take place in the next week or so and then she would like to interview you a few months later. The interview would take place in the venue of your choice, for example your own home or another location of your choice. All travel expenses would be paid. Each interview would take approximately one hour. With your permission, the interviews would be recorded so they can be written up (i.e.

typed) later. This will mean we will be able to capture everything in your own words. Only members of the research team at Oxford Brookes University would have access to the data and it would be treated in strict confidence. If your spouse/partner has also agreed to take part, we would ask to interview you separately if this is acceptable to you.

If you do not wish to be involved in the study, your spouse/partner will be welcome to participate in the study. Likewise, if your spouse/partner does not wish to be involved, you are welcome to participate.

Do I have to take part?

Participation in this study is voluntary and it is up to you to decide if you want to take part. If you do decide to take part you would be given this Information Sheet to keep and be asked to sign a consent form. If you decide to take part you would be free to withdraw at any time and without giving a reason. Your partner's care will not be affected in any way if you decide not to participate.

Are there any benefits or risks of taking part in the study?

Some people may find it upsetting to talk about their experiences. You are free to tell the interviewer if there are any questions you would prefer not to answer. You can withdraw from the study at any time without giving any reason. The care of your spouse/partner will not be affected.

There are no direct benefits for you taking part, although many people do find taking to an independent researcher about their experiences helpful. However, we hope that the findings from this study will help us to inform future clinical practice and improve the way the services are run.

Part 2:

What will happen to the information I give you?

All information which you give us will be kept strictly confidential and will not be passed to anyone else. Only members of the research team at Oxford Brookes University will have access to the information and it will not be shared with the members of your clinical team. Your name and address will be removed from any information. What you say during the interview will not be passed to anyone outside the Research Team. All quotes from the interviews used in future publications will not have your name on it. Our procedures for the handling, processing, storage and destruction of all study data will comply with the Data Protection Act 1998.

What will happen to the results of the study?

The results from the study will be used to improve the care for patients with colorectal cancer recurrence and their family members. The study will help us understand what issues people face at this stage of cancer and how we can best help them. We plan to publish the results of the study in a national journal. You are welcome to receive a summary of the results if you wish to. No individual will be recognisable in any part of the write-up or article, however quotes from participants will be used to illustrate and explain points. Any quotes used will be completely anonymous; that is they will not have your name on them or include any information which would suggest the quote had been made by you.

Who is organising the study?

The study is organised by Marta Wanat, a Research Student at Oxford Brookes University. It is a collaboration between Oxford University Hospitals NHS Trust, Birmingham University Foundation Trust and Royal Berkshire University Hospitals Trust.

What do I do now?

You do not have to do anything. Marta will contact you in a few days time to answer any questions you may have and talk about the study in more detail. If you are still interested in taking part then, she will arrange a convenient time for your interview.

What will happen if I do not want to continue with the study?

You can withdraw from the study at any point in the study. Marta will contact you again before the second interview to check whether or not you are still happy to take part.

What if there are any problems?

If you have any concerns about this study or the way it has been carried out, you should contact the Research Ethics Lead in Faculty of Life Sciences. Her contact details are:

Ms Hazel Abbott
Faculty of Life Sciences
Oxford Brookes University
Jack Straws Lane
Oxford OX3 OFL
Tel: 01865 482639

Who has reviewed the study?

The study was reviewed by Oxford Brookes University and a National Research Ethics Committee.

What if something goes wrong?

Given the nature of this study, it is highly unlikely that anything will go wrong. However, if you feel you have been harmed in some way by participating in the study, you may have grounds for legal action for compensation against Oxford Brookes University.

Further information and contact details

If you would like any further information, or have any further questions concerning this research study you are encouraged to contact the Researcher, Miss Marta Wanat on 01865 485278 (marta.wanat-2011@brookes.ac.uk) or members of the research team: Professor Eila Watson on 01865 482665 (ewatson@brookes.ac.uk) or Professor Mary Boulton on 01865 485298 (mgboulton@brookes.ac.uk). Should this study have raised any particular issues for you in relation to cancer you may wish to contact your GP practice or Macmillan Cancer Support (macmillan.org.uk) on 0808 808 00 00 and/or your local Maggie's Centre, (www.maggiescentres.org). Both are organisations which provide information and support for people with cancer and their family members / carers. Should you wish to discuss taking part in research in general you may also wish to contact Macmillan Cancer Support (macmillan.org.uk) on 0808 808 00 00 and/or your local Maggie's Centre, (www.maggiescentres.org).

Appendix 8: Consent Form

CONSENT FORM



Research study: Experiences of bowel cancer patients and spouses/partners when they have been told that the cancer has come back

Name of Researchers conducting the study: Marta Wanat, Prof Eila Watson, Prof Mary Boulton and Prof Bee Wee

Instructions: Please initial the individual boxes and also provide your name, signature and the date at the bottom of the page

I confirm that I have read and understand the Participant information Sheet dated(Version...) for the above study and have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and I am free to withhold personal information or withdraw at any time, without giving any reason, and without my medical care (or the medical care of my spouse/partner) or legal rights being affected

I agree to the interview being audio recorded and typed up later

I agree to take part in this study

I agree that any quotations from my interview can be used anonymously in publication and the presentations of the research findings

I would like to receive the summary of the research findings

For Patients only

I agree that the clinical team may forward details regarding my diagnosis and treatment to the researchers after the interview

I agree for my GP to be informed about me taking part in this study

Name of participant Date Signature

Name of researcher Date Signature

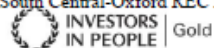
When completed: 1 for participant; 1 for researcher site file;

LREC study name: Experiences of colorectal cancer recurrence Consent Form

Version 3/ 14.5.2012

FREC study number: 2011/11

South Central-Oxford REC B study number: 12/SC/0214



www.brookes.ac.uk

Appendix 9: Participant Demographic Form

Participant Demographics

Participant Reference Number _____

Please tick the appropriate box.

Gender: M F Patient Spouse/Partner

Age: _____ **Date of Birth** _____

Current Working Arrangements: Which of these best describes your current situation?

Please tick the one that most applies.

- ¹ In full-time paid work (including self-employment)
- ² In part-time paid work (including self-employment)
- ³ In full-time education or training (including government training programme)
- ⁴ Not seeking employment (e.g. Caring for dependent children or adults)
- ⁵ Unemployed
- ⁶ Other:
please specify:

Are you currently off work because of your illness/your spouse/partner's illness?

- ¹ Yes
- ² No
- ³ Not applicable

Occupation: Please describe your current/most recent occupation:

Ethnicity: To which of the following ethnic groups would you say you belong?

Please tick one box

- ¹ White British
- ² White Other
- ³ Black – Caribbean
- ⁴ Black – African
- ⁵ Black – Other Black Groups
- ⁶ Indian
- ⁷ Pakistani
- ⁸ Bangladeshi
- ⁹ Chinese
- ¹⁰ Other:
please specify:

Education: What is the highest level of qualification you have?

Please tick one box.

- ¹ 'O' level (GCSE or equivalent)
- ² 'A' level (or equivalent)
- ³ Clerical or commercial qualification
- ⁴ College or university degree
- ⁵ Postgraduate qualification
- ⁶ None of these

Marital status: Please describe your marital status:

- ¹ Married
- ² Single
- ³ In a relationship
- ⁴ Divorced/separated
- ⁵ Widowed

Living arrangements: Please describe your living arrangements (*tick as many as apply*)

- ¹ Live alone
- ² Live with parents
- ³ Live with spouse/partner
- ⁴ Live with children

Appendix 10: Article in press

Patients' experience with cancer recurrence: A meta-ethnography

Abstract

Objective: Recurrence is a difficult stage in the cancer journey as it brings to the fore the life threatening nature of the illness. This meta-ethnography examines and synthesises the findings of qualitative research regarding patients' experience of cancer recurrence.

Methods: A systematic search of the qualitative studies published between 1994 and April 2014 was undertaken. Seventeen relevant papers were identified and a meta-ethnography conducted.

Results: Six third-order concepts were developed to capture patients' experiences: *Experiencing emotional turmoil following diagnosis*, which described the emotional impact of diagnosis and the influence of previous experiences on how the news were received; *Experiencing otherness*, encompassing changed relationships; *Seeking support in the health care system*, describing the extent of information needs and the importance of the relationship with health care professionals; *Adjusting to a new prognosis and uncertain future*, highlighting the changes associated with uncertainty; *Finding strategies to deal with recurrence*, describing ways of maintaining emotional well-being and regaining a sense of control over cancer;

and *Facing mortality*, describing the difficulties in facing death-related concerns and associated consequences.

Conclusions: This meta-ethnography clarifies the fundamental aspects of patients' experience of recurrence. It suggests that health care professionals can promote a positive experience of care and help lessen the psychosocial impact of recurrence by providing information in an approachable way, listening to patients and being sensitive to their changing needs and concerns. It also points to the importance of supporting patients in adopting strategies to regain a sense of control and to address their potential mortality and its impact on loved ones.

Background

In 2011, over 331 000 people were diagnosed with cancer in the UK [1]. Unless cancer is already advanced at the time of diagnosis, patients are usually offered surgery, chemotherapy or radiotherapy or a combination of these. If after a period of being disease free, cancer comes back, it is defined as a recurrence [2]. Despite improvement in initial cancer treatments, recurrence is still relatively common [e.g 3 4 5]. Though the risk varies across cancer types, and by stage, grade and other tumour characteristics, improvements in treatments mean many more people will live for longer with active and advanced disease [6].

Recurrence is a difficult stage in the cancer journey. It challenges patients' hopes that cancer can be cured, emphasises the life threatening nature of the illness [7-10] and highlights uncertainty about the future [11-13].

Qualitative research and qualitative syntheses have been increasingly recognised as filling an important gap in providing an understanding of patient experience to inform policy [14]. Meta-ethnography is one of the interpretative methods available to bring together evidence from qualitative research. Although it originated in the area of education [15], interest in meta-ethnography has been extended and further developed in the field of health care research [16]. It has been suggested that meta-ethnography is most suitable when looking at individuals' experiences [17]. The meta-

ethnography presented in this paper followed the approach developed by Noblit and Hare [15] further developed by Toyne and [18 19] and was conducted to explore, evaluate and synthesise the existing knowledge base regarding patients' experiences of a recurrence of cancer.

Methods

Noblit and Hare [20] identified seven stages (Figure 1), which constitute the iterative process of meta-ethnography [18].

Figure 1 1 Seven stages of Noblit and Hare's meta ethnography

- 1. Getting started**
- 2. Deciding what is relevant to the initial interest**
- 3. Reading the studies**
- 4. Determining how the studies are related**
- 5. Translating the studies into one another**
- 6. Synthesising translations**
- 7. Expressing the synthesis**

Stage one involved an initial scoping review of research on the experience of cancer which identified the experience of cancer recurrence as appropriate for a meta-ethnography.

Systematic search and critical appraisal

Stage two comprised defining the scope and terms of the search strategy and critically appraising the studies identified.

Due to well-known difficulties of indexing qualitative studies, particular attention was paid to developing a comprehensive search strategy for studies which used a qualitative methodology. As the last two decades have seen major changes in cancer treatments and health care services, it was decided to restrict the search to this period. Three electronic databases – Medline, CINAHL and Psychinfo – were searched for studies published between January 1994 and April 2014, using the search terms listed in Table 2. The grey literature was not searched. The criteria for inclusion in the meta-ethnography were that the study: a) explored the experience of patients with a cancer recurrence b) used qualitative methodology to gather and analyse results and c) were published in English.

[Insert Table 1]

While a number of tools are used in appraising qualitative studies, the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist is most commonly used in meta-ethnography [21]. All studies included in this review were appraised using the CASP tool and then coded using the coding scheme devised by Dixon-Woods: KP (key paper providing rich conceptual insights), SAT (satisfactory paper), FF (fatally flawed) and IRR (irrelevant: not meeting inclusion criteria) [22]. All papers were reviewed by one reviewer (Anonymous) and by one of two additional reviewers (Anonymous). Quality appraisal was conducted to gather information about the quality of the current evidence. It was decided not to exclude any papers

based on quality as methodologically weak papers can still provide rich conceptual insights [23].

Data extraction and Synthesis

Stage 3 involved reading the articles selected for the synthesis and re-reading for further familiarisation. As part of this process, relevant information including background, methods and results were extracted.

Stage 4 focused on determining how the studies were related. As part of this process, first order constructs (quotes from the participants) and second order constructs (key concepts and themes and their interpretation by the paper's authors) were extracted by MW and one of MB or EW independently. Second-order constructs form data for meta-ethnography and the purpose of extracting first order constructs is only to provide illustrative quotes. As Toye et al [18] have pointed out quotes provided under a particular second-order constructs are selected by authors and therefore may not illuminate all aspects of it. To aid this process, a table was created, with each second-order construct from each paper listed alongside the representative quotes from the participants [16]. Each row represented one second order construct from a particular paper.

Stage 5, reciprocal translation of the studies, involved looking at how studies were related to each other and required reading each row, comparing across studies, to consider how the constructs were

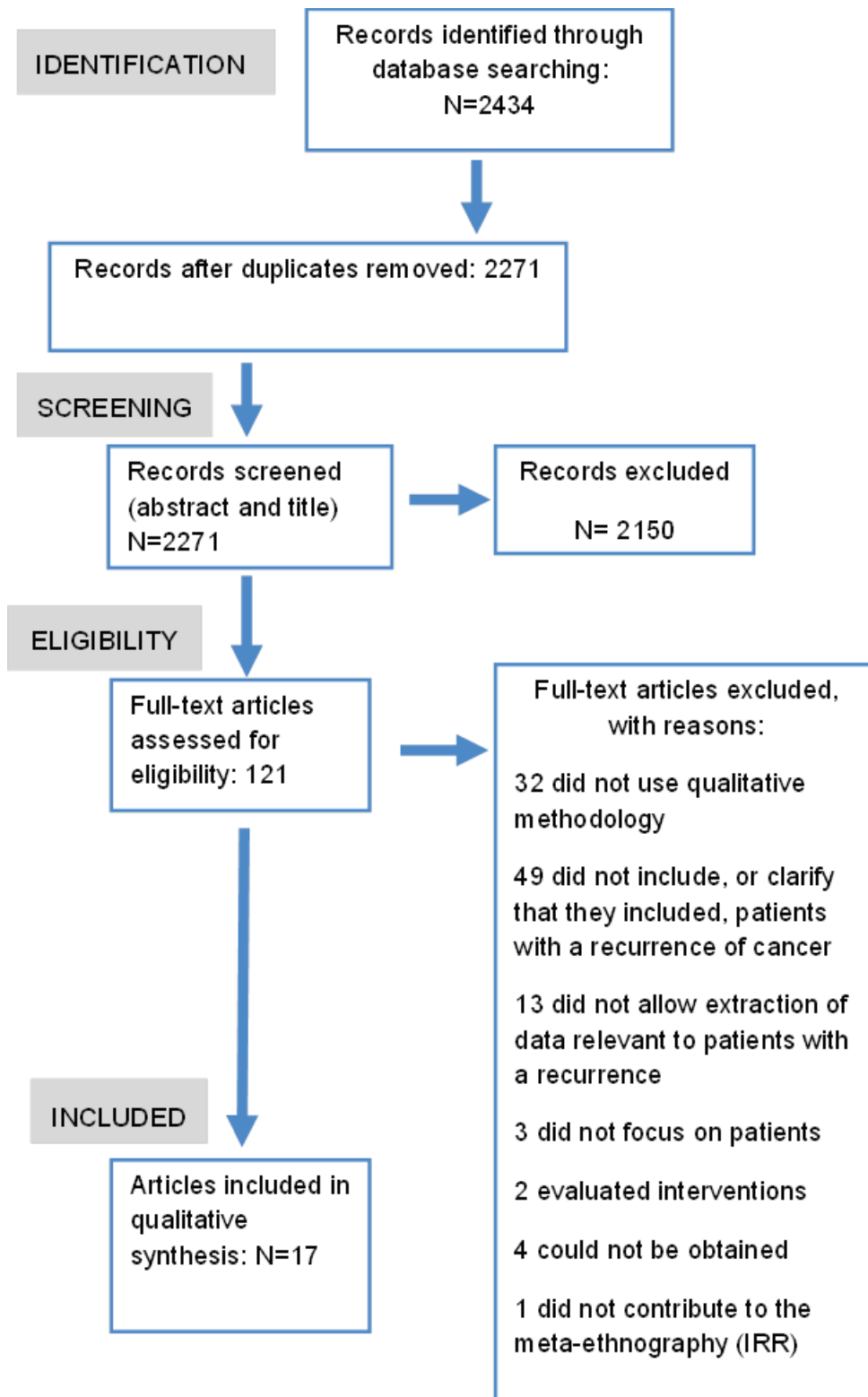
related. The focus here was on the descriptions of the second order constructs rather on the terms used.

Stage 6, synthesising translations, involved generating third-order constructs. For example, the second order construct *diagnosis of recurrence* in the study by Mahon and Casperson [9] and *emotional reactions* in Griffiths et al. [24] each contributed to the third order-construct *experiencing emotional turmoil after diagnosis*. An illustration of the process is presented in Table 1. The aim here was not only to summarise the data but to create conceptually rich third-order constructs, encompassing the dynamic experience of participants. This synthesis took form of a reciprocal translation, which is possible when studies included describe similar findings [15].

[Insert Table 1]

Results of the search

The search yielded 2271 articles after duplicates were removed. One reviewer (Anonymous) screened each abstract and two additional reviewers (Anonymous) screened a subset (10%) to establish if the paper was 1) a qualitative paper and 2) addressed the topic of interest. This initial screen resulted in 2150 articles being rejected. The remaining 121 were subjected to full text review and 103 were excluded for a number of reasons. Figure 2 summarises the screening process.



A total of 17 articles were included, based on 15 data sets. Studies were published between 1997 and 2014 and were conducted in UK, Europe (Sweden) and North America (Canada and USA). They included patients with a range of cancer types, with breast and ovarian cancer most common. The main method of data collection was individual interview but a variety of analytical approaches were used, including Phenomenology, Grounded Theory and Content Analysis. Chunlestkul et al. [25-27] conducted one study, which resulted in two publications [25-27] and Ekwall et al [7,27] conducted one study which resulted in two initial publications and, following further interviews with a sub-group of the initial sample three and five years later, they published a third paper [28]. Table 3 provides a description of all the studies included in the meta-ethnography.

[Insert Table 3]

Critical appraisal:

Papers differed in the extent to which they met the quality criteria. All papers clearly stated aims and the rationale for choosing a qualitative methodology. However, some described their chosen methodology in greater detail and displayed a more critical approach to their findings. Few explicitly considered the way the researchers' assumptions may have shaped the findings and in some papers, the analytical approach used was not made explicit. Studies also differed in the extent to which they provided rich conceptual insights. Seven were coded as a key paper, and 10 as of satisfactory quality. No papers were rated as fatally flawed.

Results

The synthesis identified wide-ranging ways in which a cancer recurrence impacted on participants. The third-order constructs developed to capture these were: *Experiencing emotional turmoil following diagnosis*, *Experiencing otherness*, *Seeking support in the health care system*, *Adjusting to a new prognosis and uncertain future*, *Finding strategies to deal with recurrence*; and *Facing mortality*.

1. Experiencing emotional turmoil following diagnosis

Diagnosis of recurrence was a distressing emotional experience for the majority of patients, generating a range of responses including shock, fear, anger, devastation or hopelessness [7 9 10 23 31]. In two studies of patients with a recurrence of oral cancer and ovarian

cancer, participants described feelings of shame and guilt for developing cancer again [7 23].

With two exceptions [10 32], the studies found that awareness of the possibility of recurrence did not lessen the emotional impact [9 10 31 32]. As one participant said: “I knew all along it could come back but let me tell you, nothing could ever prepare you for it” [9 p.183].

While experiencing symptoms facilitated detection of the recurrence for some [7 8 10 28 29], others initially attributed the symptoms to non-cancer causes [9 28 30]. For those who did not experience any symptoms and were diagnosed on the basis of a change in a tumour marker, the experience was particularly shocking [7 30].

2. Experiencing otherness

Recurrence of cancer had wide-ranging social impacts and challenged existing relationships between patients and those close to them. These challenges related to expressing feelings as well as managing changing bodies. Growing closer and sharing the burden of cancer was also part of the experience for some patients.

2.1 Experiencing difficulties in sharing the uncomfortable with others

Sharing emotional as well as physical suffering with family members was found to be challenging [7 28 29]. Negotiating disclosure of the diagnosis as well as receiving support in making decisions regarding treatment were also described as difficult by some patients [29 31 32]. Inability to express feelings and concerns about triggering

negative reactions in people could result in patients withdrawing from work or leisure activities and some studies highlighted that this made the experience for patients a lonely one [10 32 33]. The fear that they were becoming a burden and contributing to the family's suffering also hindered patients in sharing their distress [10 26 32].

Sharing feelings and preparations related to mortality and death was also challenging for some patients [26 32]. Chunlestskul and colleagues [26] and Vilhauer [32], in describing the experiences of women with metastatic breast cancer, highlighted their sense of being silenced from discussing their mortality as it made people feel uncomfortable and generated superstitious fears about bringing on death. Other patients felt that by discussing death, they could be perceived as having lost their "fighting spirit" [25 32].

While they rarely mentioned to clinicians their difficulties in discussing mortality [25], patients valued the opportunity to discuss their death-related concerns with counsellors and support groups [26]. At the same time, maintaining normality and not always being treated as an ill person was also welcomed by some participants [29 32]. The balance between being able to talk about their experience and trying to live a normal life was difficult to achieve, however, as families could sometimes be overprotective [29 32].

2.2 Managing their social lives with a changing body

Feelings of otherness were also generated by bodily changes as a result of treatment. A loss of physical ability and ongoing symptoms

caused a number of patients to reduce their daily activity and had an impact on their quality of life [7 24 29 30 33]. Accepting these physical limitations was often difficult, as it meant increased dependence on other people and losing previous roles, though support from family could facilitate adjustment to these changes [29]. An altered body image caused distress and affected individuals' well-being and their relationships with others. Side effects and changes to bodies following breast cancer treatment were perceived as disfiguring and difficult to accept [7 10 32]. Some felt that their altered bodies were a visible sign of dying and as such, triggered uncomfortable reactions from others [10 28 32 33]. For patients with oral cancer, the consequences of further treatment could affect their ability to communicate, which made them feel isolated [34].

Becoming frustrated with pain could also negatively impact on family dynamics [29]. These changes lead some people to withdraw from social activities [32], while some needed time to adjust to bodily changes before returning to previous social lives [34]. Those in intimate relationships experienced changes to sexual life [7 11] while those wanting to form relationships perceived it as a barrier [32].

A diagnosis of recurrence also seemed to create a number of changes to the daily rhythms of participants' lives, which had to be negotiated within the context of their social relationships. Patients' decisions on whether or not to undertake activities were often influenced by fluctuating periods of deterioration and recovery, which families sometimes struggled to adjust to [33]. The need for support

also depended on the illness cycle, which other people sometimes found difficult to understand [32]. Relentless treatment regimens meant the loss of capable bodies and demanded constant adjustment. This often resulted in careful monitoring of their bodies and sensitivity to changes [33].

2.3 Connecting and growing with people

For some, a recurrence of cancer resulted in positive changes to relationships. Being able to share death-related concerns was appreciated and facilitated growth and feelings of closeness with families and other cancer patients [25 26]. An awareness of the fragility of life and facing one's mortality could also contribute to a greater appreciation of family and friends [7 27 35]. Social and practical support from family as well as other cancer patients lessened the distress, gave them strength to carry on [8 34] and helped in accepting and living with the limitations of the illness [8 29 34 35].

3. Seeking support in the health care system

Interaction with health care professionals when re-entering the system following the news of recurrence was an important part of patients' experience. *Seeking and negotiating medical information* and *Wanting to be known and valued by clinicians* were important components of that interaction.

3.1 Seeking and negotiating medical information

Information provision and communication were integral to patients' experience of recurrence. Dealing with information about prognosis was a complex process carefully negotiated between patients and clinicians. Both patients and clinicians searched for clues on how to talk about prognosis [36]. This was well described by Step and Ray as the "prognosis dance", as illustrated by the following participant: "*She wanted to tell me as little as possible to get me through to the next step and I pushed a bit*" [36 p.54]. The amount of information wanted and needed by patients varied. Some wanted greater recurrence-specific information, including prognosis, treatment options, reasons for recurrence and risks of further recurrences [7 31 36 37] and carefully sought the required information [36], while others found this level of information overwhelming [8 29]. Information provision could lessen anxiety and facilitate understanding of the situation. Although the clinical team was seen as the main source of information, some also wanted, but did not always get, access to other cancer patients with a recurrence to share information and experience [8 31]. Some participants also described the need to be more proactive in order to obtain the information they wanted regarding treatment and prognosis [30]. Terminology related to cancer recurrence was also found to be confusing for patients, especially when compared with information provided at the initial diagnosis. This often left them to interpret things on their own [36]. In contrast, two studies described how information at the initial

diagnosis facilitated their understanding of the situation at times of recurrence [8 9].

3.2 Wanting to be known and valued by clinicians

The nature of the relationship was also found to be an important factor contributing to either positive or negative experiences of health care at the time of recurrence. Having information provided in an approachable and sensitive way, being listened to and being offered help were facilitators of positive experiences of care [29 35 37].

Being seen as a partner to a health care professional and sharing responsibility of care with them was also seen as important [37].

Continuity of care was valued as it facilitated not only the diagnosis but also more effective and trusting relationships [8]. Conversely, feelings of being rushed, insensitive communication, use of jargon, lack of communication between staff and broken promises were inhibitors of positive experiences of care [27 35 37]. For example, Howell and colleagues found that patients with a recurrence of ovarian cancer often perceived that clinicians' attitudes had changed and felt that they had given up on them [30].

4. Adjusting to an uncertain future and a new prognosis

Following the diagnosis, worry about further disease progression was common [32 34 35] and participants often balanced awareness of the possibility of death with hope for more time. Progression of disease usually signified fewer treatment options and transition from cure to controlling active disease or symptoms [8 30 35 36]. As a participants

with ovarian cancer recurrence noted: *“I didn’t feel that I had any options, because she presented two things to me and they were dependant on the state on my health”* [8]. Those who were able to have surgery perceived it as a better option than systemic therapy [9 34 35], regardless of the lack of guarantees for cure [35]. Although longing for a break, patients continued with treatment in the hope of prolonging their lives [29 33]. The uncertainty around prognosis and changing treatment regimens could also be overwhelming for patients [37] and prevented them from having long-terms plans, which they found difficult.

Some studies highlighted that the diagnosis of a recurrence signified for patients the need to become familiar with a new disease and its implications [8 9 10]. Previous experiences of cancer could have an impact on how current experience was understood [9]. The diagnosis of a recurrence often brought a realisation that a cure may no longer be possible and that death was now a real possibility This was often in contrast to how they viewed their prognosis after initial diagnosis, which was more positive [8 10]. Equally, having experience of a previous recurrence reinforced for some the belief that remission was once more possible [9].

5. Finding strategies to deal with recurrence

5.1 Attempting to regain control over cancer

In the context of uncertainty, attempting to take control over cancer was important for patients. Taking responsibility for one’s own health

by eating well or exercising was perceived as facilitating recovery following treatment and maximising the chances of survival [7]. Adopting a fighting spirit and positive attitude were also seen as ways to aid recovery and halt disease progression [7 29 35]. Seeking second opinion and asking for a specific treatment or alternative therapies was an important part of this process. [28 30 37]. In one study of patients with metastatic cancers who were experiencing pain, patients did not always adhere to their medication as prescribed, as they felt they knew when medication was needed and chose to stop or reduce activities to control pain [31].

5.2 Taking steps to preserve emotional well-being

Taking steps to preserve emotional well-being in the context of the threat of death was an important way of dealing with the impact of cancer recurrence and studies described a variety of ways on which patients attempted to do so, including activities which restored emotional balance [25] and leaving a legacy in the form of life projects [26]. Giving up activities which were found to evoke stress, such as employment, was taken as a conscious decision by some, and aided the preservation of emotional resources [32 33]. Conversely, for some, being able to maintain pre-cancer routines could help create feelings of normality [35]. Focusing on the present, taking one day at a time and accepting losses also helped participants to deal with challenges and regain wellness [10]. Building

relationships with people and connections with nature was found useful for some patients [33]

6. Facing mortality

6.1 Having to face one's mortality

Hearing news of recurrence brought to the forefront thoughts of their mortality. Facing death and making preparations was acknowledged as emotionally challenging and required time to work through [25 26]. Participants faced the paradox of wanting to know the implications of the diagnosis, while also preferring information to be given gradually in order to allow them to prepare to face their mortality [36].

Undertaking practical preparations and relinquishing roles was part of this process [26] with some realisation that this process is never complete [25]. Patients grieved the loss of their envisaged future and the prospect of their early death [9 10 32]. Experiencing symptoms triggered thoughts of death, while periods of recovery heightened their desire for prolonged life [25].

6.2 Changing perspectives on life as a result of facing mortality

Diagnosis of recurrence provided an opportunity to evaluate previous life choices and, for a number of participants, led to a change in priorities [9 27 31], where previous concerns lost their importance [27]. Heightened appreciation of life and their remaining time was common among participants [9 10 25 26 32 33]. Engaging with their mortality enhanced self-awareness of both personal strengths as well

as weaknesses [10]. Facing one's mortality and finalising preparations for death, allowed some to live in the present [26].

Conclusions

Stage 7, expressing the synthesis, is the last of Noblit and Hare's stages and concerns the dissemination of the findings to maximise their impact. We have interpreted this from the perspective of applied health research as identifying the implications for health care practice.

This meta-ethnography has demonstrated the complexity of the issues patients face when diagnosed with a recurrence. It fills an important gap in the literature by bringing together a wide range of qualitative studies of the experiences of patients at this difficult stage. It builds on an earlier narrative review of the psycho-social impact of recurrent cancer, which included both qualitative and quantitative studies up to 2007. In addition, the interpretative nature of the current qualitative synthesis, has allowed us to develop a new conceptual understanding of the experiences of patients with a recurrence [18].

The diagnosis of cancer recurrence evoked a range of emotions including fear, anger, shame and guilt. Quantitative studies have questioned whether the initial cancer diagnosis or the diagnosis of a recurrence is more distressing and have assessed levels of anxiety

and depression at each stage [38] whereas the evidence presented in this synthesis adds to our understanding of the complexity of the emotions experienced by patients. We found no evidence that recurrence is either more or less demanding emotionally than initial diagnosis and suggest a more useful focus may be on describing the nature of their distress, rather than on measuring its intensity.

Studies also highlighted that regardless of their vigilance and knowledge that cancer can return, patients still found the news of recurrence unexpected and deeply distressing. In addition, several studies in our review found that patients initially attributed symptoms of recurrence to non-cancer causes [9 28 30]. A recent review of patients views of follow up suggested that patients see the aim of follow up appointments as providing reassurance, and that they lacked information on the effectiveness of follow up tests [39]. We would agree with the authors of this review that it is important for patients to be provided with easy to understand information regarding the aims of follow up, and to be prepared for the possibility of recurrence and what signs to look out for. It is a difficult balance for health professionals to achieve between offering hope and preparing for the worst – patient preferences are likely to vary in this regard and skilful communication is required.

The perception of recurrence as shattering hopes for cure and bringing a real threat of mortality, has also been found in reviews of the experiences of patients with recurrent breast cancer [12 13]. In

our review, these concerns seem to be magnified for those not eligible for surgery, with patients viewing surgery as the only possible route to a cure. Health care professionals could play an important role in helping patients to adjust to a changing situation by balancing hope with acceptance that a cure may not be possible.

In the context of the changing meaning of a diagnosis, information about the illness and its prognosis was important to patients, with most studies finding that patients wanted more information specific to recurrence. They valued information from both their clinical team and other cancer patients at the same stage of illness, but sometimes this was lacking. Previous qualitative studies have demonstrated that compared with mixed-stage groups, stage-specific support groups can be more helpful for patients [40]. It could be useful for health care professionals to provide them with opportunities to meet other cancer patients at stage of recurrence or signpost them to charities, which could complement support from health care professionals. Equally, providing information in a sensitive manner was also important as it facilitated positive experiences of care. Thorne and colleagues [41] point out that communication can facilitate or hinder human connection and it is important that health care professionals are sensitive to patients at this vulnerable stage.

In order to deal with uncertainty, patients tried to regain control by taking care of themselves, using complementary therapies or seeking second opinions. Previous studies have also recognised these as

facilitating hope and a sense of empowerment [42 43]. Leaving a legacy, giving up stressful activities and focusing in the present also helped patients to restore their emotional well-being. It is important that health care professionals provide support to patients to help them access self-management strategies such as these, as appropriate to their own individual circumstances.

Recurrence clearly had an impact not only on individuals but also on families and the patients' wider social context. Patients valued having an opportunity to talk about their concerns, but this was often limited with both family and the clinical team. Closer collaboration between secondary care and palliative care may be needed to facilitate these conversations. This is expressed in the vision of NCSI for Active and Advanced Disease which focuses specifically on the early introduction of palliative care services to facilitate discussions in a timely manner [44]. Equally, support is needed to assist family members to help patients face the possibility of death.

A strength of this meta-ethnography is that, in contrast to previous reviews [12 13], it has included studies of a number of different types of cancer. It has thus been possible to identify the challenges across a range of cancer types as well as those relevant to specific patient groups. A limitation, however, is the diversity of time frames used in the studies that were included. A few studies conducted interviews shortly following diagnosis of a recurrence (up to two months), some in an intermediate period (5-10 months), while some were based on

largely retrospective data gathered up to 6 years following news of the recurrence. The time between initial diagnosis and the recurrence of cancer also varied widely which may also have affected their experience of the recurrence their cancer [11].

The majority of studies in our review focused on breast and ovarian cancer, and further studies are needed to explore any specific issues regarding the impact of cancer recurrence in other cancer groups, especially bowel cancer given its high incidence and recurrence rates.

This meta-ethnography has identified, reviewed and synthesised the qualitative studies of patients' experience of a recurrence of cancer published in the last 20 years. Six third order constructs were developed to capture features common to the experience of recurrence across a range of cancer types. These constructs have provided the framework for discussing the diversity and complexity of patients' experiences and for considering the implications for health care professionals.

Conflict of interest: None

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Table 1: Search terms

1. (maximum variation or snowball).mp.
 2. (thematic\$ adj3 analys\$).mp.
 3. (participant* adj3 observ*).mp.
 4. (nonparticipant* adj3 observ*).mp.
 5. (non participant* adj3 observ\$).mp.
 6. (structured categor* or unstructured categor*).mp.
 7. action research.mp.
 8. (audiorecord* or taperecord* or videorecord* or videotap*).mp.
 9. ((audio or tape or video*) adj5 record*).mp.
 10. ((audio* or video* or tape*) adj5 interview*).mp.
 11. (content analy* or field note* or fieldnote* or field record* or field stud*).mp.
 12. (qualitative* or ethno* or emic* or etic or emic or phenomenolog*).mp.
 13. (hermeneutic* or heidegger* or husserl* or colaizzi* or giorgi* or glaser or strauss).mp.
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14. (van kaam* or van manen or constant compar*).mp.
 15. (focus group* or grounded theory or narrative* or lived experience* or life experience*).mp.
 16. (theoretical sampl* or purposive sampl* or ricoeur or spiegelber* or merleau ponty).mp.
 17. IPA.mp.
 18. interview*.mp.
 19. biographical.mp.
 20. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
 21. adjustment.mp.
 22. perception.mp.
 23. "information need*".mp. [mp=ti, ab, ot, nm, hw, kf, px, rx, ui, tc, id, tm]
 24. "supportive need*".mp.
 25. "supportive care*".mp.
 26. experience*.mp.
 27. psycho-social.mp.
 28. psychosocial.mp.
 29. psycholog*.mp.
 30. social.mp.
 31. adaptation.mp.
 32. information*.mp.
 33. 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28
 34. (cancer* or carcinoma* or malignan* or tumour or tumor or
-

neoplasm*).mp.

**35. (secondar* or recur* or relapse* or metasta* or
advanced).mp.**

36. 34 and 35

37. 20 and 33 and 36

38. limit 37 to English language

39. limit 38 to humans

40. remove duplicates from 39

Table 2: An example of the first and second-order extraction:

Third order construct	Paper	Second-order constructs	Description of the second-order construct	First order construct (quote from the participants)
Fears of recurrence becoming a reality	Mahon and Caspersen [9]	Diagnosis of recurrence	Participants experienced a variety of symptoms and attributed them initially mainly to non-cancer causes. They described the emotional reactions of being overwhelmed and shocked even though being prepared for recurrence.	<i>I knew all along that it could come back but let me tell you, nothing could prepare you for it. Even though I knew it was happening. I got real lightheaded when doctor told me.</i>
Fears of recurrence becoming a reality	Griffiths et al. [27]	Emotional reactions	Participants described the emotional impact of diagnosis including shock, devastation, emotional vulnerability and hopelessness. Also experienced intense feelings of shame, often related to feeling a burden	<i>I just felt numb. I was speechless.</i>

Table 3: Studies descriptions

Study and	Country	Sample N	Time since	Length of	Methods of	Methods of	Aim
Dixon-Woods et al. (2004) Coding (K=Key paper, SAT-satisfactory, FF- fatally flawed IRR -Irrelevant)	setting	(age, gender and cancer site: primary)	the initial diagnosis	time with diagnosis of recurrence	data collection	data analysis	
Chunklests kul et al. [26] K	Canada	N= 5 women, 44-72 years breast	16-18 years	2-6 years	Open –ended interviews on two occasions	Phenomenolog ical approach (not defined)	To explore the lived experiences of women with metastatic breast cancer in preparation for their death
Chunklests kul et al. [25] K	Canada	N= 5 women, 44-72 years breast	16-18 years	2-6 years	Open –ended interviews on two occasions	Phenomenolog ical approach (not defined)	To examine enabling and impeding factors in death preparations

Coward and Wilkie [28] SAT	USA	N=20, 10 women and 10 men, 26-73 years, breast, lung, bladder, prostate, kidney and thyroid	1-13 years	1 month- 8 years	Semi-structured interviews	Not specified	To explore gender differences in experience of metastatic bone pain
Dooks et al. [34] SAT	Canada	N=9, 1 woman and 8 men, 60-75 years oral	-----	6-12 months	In depth interviews	Interpretative descriptive approach by Sally Thorne	To describe patients' experience of reintegrating into community following

						(1997)	surgery
Ekwall et al. [7]	Sweden	N=12 women, 50-74 years ovarian	1-5.7 years (Mean=2.8)	5-10 months	Interviews	Phenomenolog ical method (Giorgi and Giorgi, 2003)	To explore experiences of women diagnosed with recurrent ovarian cancer and its impact on daily lives
SAT							
Ekwall et al. [37]	Sweden	N=12 women 50-74 years (Median=57.5) ovarian	1-5.7 years	5-10 months	Interviews	Qualitative content analysis: Grundheim and Lundman (2004)	To explore what women with recurrent ovarian cancer perceive as important in their communication with the health care team
K							

Ekwall et al. [33] K	Sweden	N=4 women, 46-69 years, ovarian	6-10 years	3 years and 5 years	Open- ended interviews on two occasions (3 and 5 years after recurrence)	Phenomenological approach (Giorgi, 2009)	To explore the phenomenon of living with recurring ovarian cancer
Elit et al. [8] SAT	Canada	N= 26 women, 44-77 years, ovarian,	6-36 months	2 months	Semi-structured interviews;	Unspecified Content analysis;	To explore treatment decision making process and experiences of women with recurrent ovarian cancer

Griffiths et al. [27]	UK	N=9, 6 women and 3 men, 63-85 years, oral	-----	1-8 weeks	Semi-structured interviews	Grounded theory approach	1) To investigate the psychosocial responses of patients with oral cancer recurrence; 2) To highlight the key psychological issues
Howell, Fitch and Deane [30]	Canada	N=12 out of 18 women had recurrence; ovarian	-----	-----	Semi-structured telephone interviews	Not specified; coding scheme developed and used by all authors	To explore the experience of women with ovarian cancer
MAHAR AND DE VRIES [29]	UK: London	N=8, 5 women and 3 men, 48-74 years, myeloma	-----	-----	Unstructured interviews	Theoretical framework of Hermeneutic phenomenology; thematic	To explore how the experience of living with relapsed myeloma had affected the quality of

						content based	life of patients
						on method of	
						Colaizzi (1978)	
Mahon and Casperson [9] SAT	USA	N=20, 26-72 years (Mean=54); type not specified	8-94 months, (Mean=37 months)	30 days	Unstructured and semi-structured interviews	Not specified; Software used	To describe the meaning of a recurrence of cancer to the patient and possible differences between initial diagnosis and recurrence
McCahill and Hamel- Bissell [35] SAT	USA	N=12; 5 women and 7 men, 45-75 years, colorectal	-----	-----	In depth semi-structured interviews	Phenomenological approach; Three step analysis using Colaizzi	To explore the lived experience of patients who experienced surgery for CRC liver

						method (1978)	metastasis
Misra et al. [31] SAT	Canada	N=15, 12 women and 3 men); thyroid	1-21 years (Median= 5)	11-79 months (Median=24)	Semi- structured interviews	Unspecified thematic analysis combined with grounded theory	To explore the individual patient experiences relating to diagnosis and surgical treatment of loco-regional recurrence of thyroid cancer
Rose, Spencer and Rausch [45] IRR	USA	N=17, ovarian	-----	-----	Interviews	Phenomenolog ical method by Colaizzi (1978)	To explore how patients with ovarian cancer recurrence experience humour

Sarenmain et al. [10]	Sweden	N= 20 women, 55-81 years; breast	Median= 68 weeks	2 weeks- 24 months	In depth interviews	Grounded theory: Glaser and Strauss 1967 and Glaser (1978)	To explore the main concerns of women with breast cancer recurrence and how they deal with breast cancer recurrence
Step and Ray [36]	USA	N=30 women, 42-84 years, breast, lung, gynaecological and head and neck	7.3 years	-----	Interviews	Thematic analysis (not specified)	To explore patients' experience of communication at time of initial diagnosis and recurrence
Vilhauer [32]	USA	N=14 women; Mean age: 51.6 years , breast	-----	Mean =25.8 months	Telephone interviews	Content analysis	To investigate the experiences of women with metastatic breast cancer